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Living long or living well :

the dilemma for older people considering dialysis

by

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Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

The research detailed in Chapter 3 (in the publication "Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life", and other reports in the chapter) received approval from the Tasmanian Health and Medical Human Research Ethics Committee; approval number: H0013482.

The research project detailed in Chapter 4 (in the publication "Validation of the IPOS-renal symptom survey in advanced kidney disease: A Cross-sectional study") received approval from the Tasmanian Health and Medical Human Research Ethics Committee; approval number: H0016005.

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Publications

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2. Raj R, Thiruvengadam S, Ahuja K, Frandsen M, Jose M. Shared decision-making in older adults with advanced renal disease: A scoping review of the information available (submitted for publication; undergoing editorial review with BMJ Open)

3. Raj R, Ahuja K, Frandsen M, Jose M. Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life. Nephrology 2017; 22(3) 228-233; DOI: 10.1111/nep.12754

4. Raj R, Ahuja K, Frandsen M, Murtagh FEM, Jose M. Validation of the IPOS-Renal Symptom Survey in Advanced Kidney Disease: A Cross-Sectional Study. Journal of Pain and Symptom Management 2018; 56(2) 281-287; DOI: 10.1016/j.jpainsymman.2018.04.006

5. Raj R, Brown B, Frandsen M, Ahuja K and Jose M. Enabling good outcomes in older adults on dialysis: A qualitative study. (submitted for publication; undergoing editorial review with BMC Nephrology)

Presentations

Research findings reported in the thesis have been presented (oral presentations) at the following meetings:

1. Kidney Health Australia Consumer Forum, Devonport, Tasmania, Australia, 2015.

2. Regional meeting of the Renal Society of Australia, Launceston, Tasmania, Australia, 2016.

3. Physicians' Grand Rounds, Launceston General Hospital, Launceston, Tasmania, Australia, 2016.

4. Annual Supportive Care Conference, St George Hospital, Sydney, Australia, 2016.

5. Victoria-Tasmania Renal Group Scientific Meeting, Melbourne, Australia, 2017.

6. Regional meeting of the Renal Society of Australia, Launceston, Tasmania, Australia, 2017.

7. Two presentations at the Annual POS Workshop and Conference, King's College, London, United Kingdom, 2018.

8. Physicians' Grand Rounds, Launceston General Hospital, Launceston, Tasmania, Australia, 2018.

9. Renal group meeting, Princess Alexandra Hospital, Brisbane, Australia, 2018.

10. State Annual Scientific Meeting of the Royal Australian College of Physicians, Burnie, Tasmania, Australia, 2018.

11. Annual Scientific Meeting of the Indian Medical Association of Tasmania Launceston, Tasmania, Australia, 2019.

12. Nephrology Grand Rounds, University of Alberta Hospital, Edmonton, Canada, 2019.

Awards arising from the work contained in this thesis

An oral presentation of the results of the study entitled "Validation of the IPOS - Renal symptom survey" at the annual POS conference/workshop at the Cicely Saunders Research Institute, Kings College Hospital, London, UK in 2016 received the award for the best clinical research paper.

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List of Abbreviations

ANZDATA	Australia New Zealand Dialysis and Transplant Registry
AV fistula(e)	Arteriovenous fistula(e)
BMJ	British Medical Journal
CGS	Comprehensive Geriatric Assessment
CKD	Chronic Kidney Disease
CM	Conservative Management
CRI	Chronic Renal Insufficiency
CRP	C-reactive protein
eGFR	estimated Glomerular Filtration Rate
ESKD	End-Stage Kidney Disease
HD	Hemodialysis
HRQOL	Health-Related Quality of Life
IPOS-Renal	Integrated Palliative Outcome Score - Renal
IPQ - R	Illness Perception Questionnaire – Revised
KDQOL-SF	Kidney Disease Quality of Life - Short Form
KDCS	Kidney Disease Composite Score
MCS	Mental Composite Score
NHMRC	National Health and Medical Research Council
PCS	Physical Composite Score

PD	Peritoneal Dialysis
Pmp	(Patients) per million population
QOL	Quality of Life
RRT	Renal Replacement Therapy
SONG	Standardised Outcomes in Nephrology Group
SWIFT	Symptom Monitoring WIth Feedback Trial
UTAS	University of Tasmania
WHO	World Health Organisation

Abstract

One in three Australians are at increased risk for kidney disease. Involvement of the kidney can occur as a primary event, with a process that starts in the kidneys, or arise as a complication of other systemic illnesses, most notably systemic hypertension and diabetes mellitus (both of which are common afflictions, seen in about 6 million and 1.7 million Australians respectively). Patients who develop kidney involvement run the risk of progression of the illness to terminal, end-stage kidney failure. Once organ failure has set in, patients will require close monitoring and intensive treatment; such patients are often offered dialysis treatment or kidney transplantation, depending on circumstances. Currently, about 13,000 adults in Australia are being treated with dialysis therapy for end-stage kidney failure.

Dialysis was initially conceived as life-sustaining therapy, used until the kidney function recovered. Over the years, indications have expanded, and treatment is now continued even when there is no hope of recovery of renal function, in a pathway referred to as maintenance dialysis. Many countries now provide dialysis free of cost to patients; this is obviously not possible in resource-poor environments.

Dialysis typically consists of the removal of excess fluid and metabolic waste by exchanging these substances across a semipermeable membrane. There are two common types of dialysis: haemodialysis, where an artificial semipermeable membrane is used to remove waste from the bloodstream, and peritoneal dialysis, where fluid is instilled into the abdomen and the patient's own peritoneal membrane is used as the filter. Dialysis can be performed either within a dialysis unit or in a patient's home. The

latter requires that patients be trained to perform dialysis by themselves and therefore is not suitable for everyone.

Dialysis treatment is not without problems. Patients undergoing this treatment have a high mortality rate, mainly contributed by accelerated cardiovascular disease. Dialysis is an intrusive treatment, requiring patients to undertake sweeping changes in lifestyle and to commit large periods of time to therapy. While continuing on dialysis, several patients, especially the elderly, suffer progressive functional and cognitive impairment, with a low quality of life. In some older patients with multiple other coexisting illnesses, starting dialysis may not significantly prolong life either, calling into question the benefit from undertaking this complex treatment. Such patients may actually be better managed with conservative, non-dialysis pathways of care. These considerations are relevant since across the world, the number of older individuals on dialysis treatment is increasing. For instance, those aged 65 and over are the fastest growing demographic group among patients new to dialysis in Australia.

When contemplating treatment options, the length of survival with or without dialysis is the outcome most commonly considered by patients, clinicians and researchers. However, patients and families have other concerns too, such as quality of life and independence. Clinicians are faced with a relative paucity of data regarding these other outcomes that matter to patients. Doctors may even avoid discussions about unfavourable consequences, particularly if they find such conversations uncomfortable. The actual, day-to-day experience of dialysis, and the significant changes required to patients' lifestyles are not discussed very often. With inadequate information, patients may tend to simplify the choice between dialysis treatment or conservative management as simply a choice between living longer or dying sooner. Inappropriate

selection of therapy could lead to consequences such as deteriorating quality of life, worsening frailty, increasing morbidity or unexpected short survival.

Significant numbers of patients regret the decision to start dialysis or withdraw from therapy after starting. In Australia in 2017, withdrawal from dialysis was the most common cause of death among patients on dialysis; 82% of these withdrawals occurred in those 65 and over, and a third of all withdrawals occurred for psychosocial rather than medical reasons (source: ANZDATA annual reports for 2018). Against this backdrop, we were interested in studying the experience and outcomes of treatment among elderly individuals and investigating whether they could be predicted or modified so that poor outcomes and needless suffering could be avoided.

We used various analytic approaches. Through means of an extensive scoping review, we collected information available in the literature that was likely to be useful in discussing outcomes of treatment of end-stage kidney disease with patients and their families. We also analysed quality of life through the lens of symptom burden, with the understanding that physical symptoms have significant effects on health-related quality of life. We explored important clinical outcomes for patients through qualitative research, by conducting semi-structured interviews that elicited patient perspectives.

The scoping review format was used for the literature review in order to gather all the available information from a wide variety of sources, both published and 'grey' literature. The main questions addressed in the review were as follows: markers of survival, factors influencing quality of life, available information about the lived experience of dialysis in older patients, and finally, the described information needs of older patients and their carers. We published the protocol for the scoping review beforehand in a reputed open-access journal. In the review, 248 articles were included for final analysis after 15,445 were screened. Research that studied prognostic factors

was highlighted; details of prognostic indices for older people were collected and comparisons provided between conservative management and dialysis. Relatively few articles addressed quality of life. We classified the factors affecting quality of life into modifiable (e.g., symptom burden, physical status/functional ability, frailty, nutrition, depression) and non-modifiable (e.g., age, number of comorbidities) groups. With data from the lived experience of older adults with end-stage kidney disease (ESKD) and descriptions of their information needs, we provided a summary of areas to be covered in discussions with older patients regarding treatment options.

We surveyed our dialysis population and demonstrated a significant symptom burden. This burden was similar in older (age greater than 70 years) and younger patients. The symptom burden was correlated with quality of life. We also showed that symptoms were poorly recognised by nurses and doctors caring for these patients. This could potentially be one of the reasons for a low quality of life in the dialysis population.

In order to improve symptom recognition, the use of patient-completed symptom surveys is recommended; we validated the IPOS-Renal symptom survey – the most widely used survey in Australian dialysis patients today - in a separate study. This was the first published validation study of this commonly-used symptom survey. These findings generated two peer-reviewed publications and were also submitted at conferences as posters and oral presentations.

Our qualitative study asked older people about their outcomes on dialysis and the factors influencing these outcomes. We identified themes of loss (of independence, of time, of activities undertaken prior to starting dialysis) and uncertainty (uncertain future, cyclical symptoms, unpredictable tiredness after dialysis sessions) as factors contributing to poor outcomes. Meanwhile, acceptance and adaptation, with the

support of carers and healthcare professionals were the common themes among factors enabling better outcomes.

Our recommendations for clinicians advising older patients with end-stage renal failure include the use of prognostic indices, documentation of symptoms using patient-completed surveys, exploration of patient expectations, extensive discussions about the potential impact of treatment on lifestyle, the tailoring of information to suit learning styles of older individuals and the need for baseline assessments of nutritional status, physical and cognitive function. To ensure good outcomes in those that choose dialysis, we recommend ensuring appropriate skill-sets in staff assisting with dialysis treatment (particularly needling of AV fistulae), making efforts to ensure physical comfort in dialysis units, fostering relationships between patients and staff and focusing on the needs of carers.

Prognostic uncertainty can never be completely resolved, and these difficult decisions about treatment will continue to be made based on individual circumstances. During this process, it is the duty of the clinician to provide relevant, patient-centred advice in an easily understandable format. Regardless of their choice of therapy, patients ought to be well informed, supported and regularly monitored. We have suggested practical measures for clinicians to achieve these goals.

Chapter 1: Introduction

The kidneys are small, fist-sized organs situated in the upper abdomen, below the rib cage, protected by layers of muscle posteriorly and the intra-abdominal organs and muscles anteriorly. They are not easily accessible to touch or auscultation. These silent workhorses receive 20% of cardiac output and continue to function throughout the lifetime, with no periods of rest. The kidneys are responsible for maintaining the milieu interior (1). They fulfil a central role as a "metabolic filter" and are the major excretory organ for soluble waste and water. Diseases of the kidney are usually insidious and slowly progressive, causing very few symptoms until advanced stages are reached. When patients with kidney failure become symptomatic, these symptoms are vague and often not attributed to kidney disease.

On occasion, however, kidney failure can be acute and dramatic. The need to treat acute kidney failure developing in injured soldiers during conflict accelerated the advancement of dialysis therapy - a temporary treatment that helped remove metabolic waste and water with the use of filters and extracorporeal circulation (2). Over the years, the indications for dialysis have broadened. Today, patients with irreversible kidney failure are regularly supported with dialysis treatments. Such treatment continues indefinitely, unless either the kidney function recovers or the patient receives a kidney transplant. While initially a scarce resource, dialysis is now widely available. It is important to recognise that dialysis is one of the rare life-sustaining treatments that is paid for by providers such as governments or insurance agencies even though the treatment is not curative.

Dialysis is an expensive therapy to provide (3). Patients on long-term dialysis often suffer from other comorbid illnesses and also require frequent hospitalisations and

medical attention. Dialysis patients suffer an increased risk of sudden death and cardiovascular complications. Physical and cognitive decline is common (4–7). It is an intrusive treatment, placing huge demands on time and requiring significant changes in lifestyle. Thus, although dialysis prolongs life once the kidneys have failed, it does so at a significant cost.

Across the world, as societies age, the average age of patients on dialysis is also increasing. The adverse effects of dialysis are perhaps most acutely felt by older individuals who require the treatment, with the benefits of treatment decreasing progressively as age advances to beyond 65 to 70 years. Significant changes to lifestyle, functional deterioration and cognitive impairment are common complications in the elderly on dialysis. Recent research has suggested that in the elderly, particularly if they have multiple other illnesses, dialysis does not significantly prolong life. Where prognosis is poor and life prolongation is no longer guaranteed, the value of dialysis treatment becomes questionable. This situation has prompted the development of "maximal conservative therapy" or "conservative management without dialysis" (8–14). Patients undergoing this treatment pathway receive holistic, complete care for kidney failure, with a focus on symptom management, but does not include dialysis (15). In appropriate patients, such conservative management can have good results (16–18).

In conventional practice, patients are introduced to treatment options for their kidney failure as the estimated glomerular filtration rate (eGFR) drops from normal values of >90 ml/min (per 1.73 m^2 body surface area) to values around or below 25 ml/min. Patient education at this stage comprises of information about treatment of end-stage kidney disease as well as about measures to slow the progression of kidney disease. Traditionally, an incremental model of information provision is followed, with patients

receiving more and more detail regarding treatment as kidney function worsens. As the eGFR reaches around 15 ml/min, patients are expected to have decided on a treatment option. This is often difficult for patients, since at this level of eGFR, they often do not have overwhelming symptoms. In other words, they are choosing between life-altering treatment options for an abstract, potentially symptomatic stage in the future. The lack of symptoms at the time of decision-making is a problem, leading some patients to postpone the decision, or to turn to health professionals or other patients with similar illnesses for advice. If the benefit from dialysis is itself ambivalent, this adds further uncertainties to the decision-making process - and this is often the situation for older patients (19).

For the older patient contemplating treatment options for ESKD, the unpredictable results from dialysis treatment raise a decisional dilemma. Such patients have to choose between undertaking dialysis treatment with its uncertain survival benefit or undertaking non-dialysis, conservative management which carries the real risk of a shortened life span. Once more, these decisions are to be made at a time when there are very few severe or troubling symptoms. Understandably, they turn to their healthcare providers for advice. The renal specialist (nephrologist) often leads these discussions. These are difficult conversations. Research suggests that nephrologists are often not comfortable discussing poor prognosis (20,21). Although there are many reasons why nephrologists find these discussions difficult, a prominent concern is the uncertainty of outcomes, regardless of the treatment options chosen. Medical decision-making has moved from "paternalistic medicine" practices to patient-centred paradigms. In other words, whereas at one time doctors considered options, weighed the information and advised the patient on the decision to be taken, today the expectation is "shared decision-making" where the physician and patient (and carers) discuss the available

information and arrive at decisions that are consistent with the patients' values and expectations (19).

Clinicians involved in discussions around dialysis treatment are expected to behave as experts, and to provide the information required in this setting. The patients' expectations, anxieties, preferences and values are an important component of shared decision-making. The process of information exchange, including the setting, communication skills of the clinician and the learning styles of the patient are also relevant. The ultimate goal of the shared decision-making process is to arrive at a treatment recommendation that is most likely to provide the best outcomes for the patient. Optimally, the clinician should tailor discussions to the patients' information needs and expected outcomes (22).

Uncertainty about outcomes complicates these discussions. In everyday practice, nephrologists encounter some older patients who thrive on dialysis treatment despite its limitations whereas other older patients deteriorate and suffer with the treatment. Predicting outcomes in each individual patient is not easy. While prognostic indices offer some information about patient characteristics associated with poor survival, it is much more difficult to predict other, non-survival outcomes. This is paradoxical, since patients are often concerned equally about outcomes other than survival when they take on lifelong treatments such as dialysis. This inability to predict outcomes other than survival, the lack of clarity around these outcomes and the absence of sufficient information regarding patients' perceptions of outcomes on dialysis are all significant gaps in the literature. This thesis is directed at exploring outcomes with treatment of ESKD in the elderly and seeks to address these gaps.

Exploration of outcomes encompasses a vast area of study. Broadly, potential outcomes after undertaking a treatment pathway for kidney failure can be divided (as discussed

above) into survival outcomes and non-survival outcomes. The latter include outcomes such as quality of life. In fact, when patients consider treatment choices, they sometimes make the distinction between "quantity of life", referring to the prolongation of life provided by dialysis in opposition to "quality of life", a concept that is difficult to define, but is related to individual values and expectations. Quality of life has different meanings for different people. In medical literature, one speaks of an overall quality of life of which health-related quality of life is an important subset. Health-related quality of life has been well studied. In addition to several other factors, biophysical factors and symptom burden are important components of health-related quality of life (23). If one were to broaden the concept of "outcome", then patient perceptions of outcome are important as well. Ultimately, it is the patients' judgement of their outcome that speaks to the success or failure of the treatment chosen.

The focus on patients' values is spreading to other aspects of research in kidney diseases. For instance, there is a perception that the results commonly reported in research papers today may not often be directly relevant or useful to clinicians working in the field or to patients themselves (24). This impacts on the practical value of research outputs and is potentially wasteful of resources. An approach to tackle this divide (between what is important to stakeholders versus what is actually studied by researchers) has been to establish what the outcomes valuable to stakeholders are, through a rigorous, validated process. Once these outcomes are identified and published, the research community knows where stakeholders' interests lie. Subsequent research could focus on these valuable outcomes, or include the effects on these outcomes in the research reports. Potentially, this would reduce wasteful research, enable better translation of research into practice and enable comparisons between different interventions using common comparators. For instance, considering that fatigue is identified as an important problem by patients and clinicians, a study on an

intervention to treat anaemia might report not only the effect on improving laboratory tests of haemoglobin, but also the effects on improving fatigue (25). Such an approach to reporting results comes from the belief that current research ought to address the outcomes that have been rigorously studied and found to be important to patients, clinicians and policy-makers. These principles are the basis for the establishment of the Standardised Outcomes in Nephrology (SONG) initiative, launched in 2014 (26). The effort recommends the identification of core outcomes important to all stakeholders within each research area in Nephrology, using validated processes. The effort has recommended the inclusion and reporting of these core, standardised outcomes in trials involving patients undergoing various forms of dialysis, transplantation or in specific patient groups (27,28). These recommended outcomes have been endorsed by several renal and research organisations, paving the way for their widespread use and adaptation (26).

In planning the research associated with the exploration of outcomes in this thesis, the areas I chose to work on reflected the considerations discussed here. A systematic review of literature summarised the factors to be considered (survival and other outcomes) in the elderly with advanced kidney disease. A separate line of research studied symptom burden, its effects and the recognition of these symptoms by clinicians, with the understanding that not only are symptoms important to patients, but they also contribute to health-related quality of life (23,29,30). As discussed above, symptoms are only one group among the many contributors to health-related quality of life. A detailed description of the models of quality of life and the influence of symptoms is resented in Chapter 3. Lastly, qualitative research was undertaken, in the form of analysis of semi-structured patient interviews, attempting to obtain the patient perspective regarding outcomes on dialysis.

In the following paragraphs, the background to the thesis is presented, followed by further discussion of the research studies included here and finally, an overview of the thesis publication itself.

1.1 Background: The Ageing population on dialysis, and their outcomes

1.1.1 Incidence and prevalence of kidney failure and dialysis among older patients: Australian experience

In 1998, there were 5536 patients on dialysis in Australia. Twenty years later, at the end of 2017, that number had more than doubled to 13,051. The prevalence of dialysis per million population rose from 298 to 531 during the same period. In 2017, people between 75 – 84 years had the highest prevalence of renal replacement therapy (which includes dialysis and transplantation), followed by those aged between 65 – 74 years, and then by those aged 55 – 64 (2926, 2693 and 2099 patients per million population [pmp] respectively) (31). When considering the relative incidence (i.e., new patients starting treatment in 2017) among population groups, the highest incidence was in those aged 75 – 79 (459 pmp), followed by those 80 – 84 (433 pmp) and those 70 – 74 (414 pmp) (32). Therefore, the Australian population with end-stage kidney disease has a high proportion of older individuals both in terms of existing patients (prevalence) and in terms of those new to treatment (incidence). Similarly high incidence rates in the elderly have been reported for the end-stage renal disease populations in the USA, UK and Europe (33–35).

1.1.2 Outcomes on dialysis for older persons: Mortality

Dialysis in older adults continues to be associated with very high mortality rates. The 5-year survival rate in those aged 75 – 84 years was 33%, in those aged 65 – 74 years it was 50%. Median survival in the same age groups was 3.5 years and 4.7 years respectively (32). These survival rates are worse than several types of disseminated cancer (36).

1.1.3 Outcomes on dialysis for older persons: Outcomes other than mortality

There are several outcomes other than mortality that are significant for the older individual. Some of these include (8,20,37–44):

- Preservation of functional capacity
- Preservation of mobility
- Avoiding fatigue and its effects
- Preservation of cognitive function
- Forced assumption of the 'sick role', as a result of
    - Restriction of activities away from dialysis
    - Changing social interactions
    - Progressive physical and cognitive deterioration
    - Post-dialysis fatigue and limitations imposed

Discussions about outcomes on dialysis ought not to be restricted only to survival. Dialysis is a very intrusive treatment, and its effects are felt in all aspects of life. Older patients on dialysis have a lower quality of life, greater functional deterioration, persistent symptoms such as fatigue and a significant impact on life-roles. This is often

compounded by significant regret regarding the decision to start dialysis and reports that the information provided before starting dialysis was inadequate (45–47).

When quality of life is measured objectively using surveys, older patients on dialysis, like the younger counterparts, continue to have a lower overall score compared to their peers without renal disease. The biggest restrictions for dialysis patients are seen in physical attributes of quality of life (48).

Patients with CKD already have worsening functional status as their disease progresses. Studies have shown worsening physical status as disease advances, and an already low functional status at dialysis initiation (49–51). Worryingly, this low physical activity status at dialysis initiation is also associated with subsequent mortality and with poorer quality of life (52,53). As can be expected, patients who maintained their physical activity status after the initiation of dialysis did better, both in terms of survival, and quality of life (54,55).

The risk of physical deterioration appears to be most significant in the initial months after dialysis initiation. Jassal and colleagues showed in 2009 that 30% of patients over the age of 80 who initiated dialysis suffered functional deterioration requiring support in the first 6 months after dialysis initiation (56). In a Dutch study of the trajectory of physical function after initiation of dialysis, only 15% were able to maintain functional ability at 2 years - the rest had either died or worsened in status (57). In the same study, increasing age was associated with worsening physical status. Just 3.6% of those ≥75 years old maintained a good physical condition after 2 years. This progressive functional decline is especially worse among those who are already in nursing homes at the time of initiation. A study from Kurella-Tamura and colleagues found that up to 87% of institutionalised patients suffered further functional decline within the first year (58).

Another constant for patients on dialysis is the symptom burden. Symptoms in dialysis are often quite severe, and the burden of symptoms are sometimes considered as bad as the burden in patients with advanced cancer (59). A typical example of a common symptom, not well relieved by dialysis is fatigue. Fatigue is a major concern for patients already established on dialysis (60). Associations with fatigue include older age, high ultrafiltration rates, anaemia, inflammation as evidenced by a raised CRP, pain and poor sleep, among other factors (61). Post-dialysis fatigue is especially common in the older patient and can have significant negative effects on quality of life. If post-dialysis fatigue forces patients to rest in bed for a while after dialysis, for instance, this means that even more time is taken from normal activities beyond the time already surrendered for undergoing dialysis. Thus, persistent fatigue is one of the outcomes of dialysis that can have potentially significant effects on quality of life and is a factor that older patients need to consider when making treatment choices.

Frailty is a concept that is becoming increasingly relevant for the dialysis population. Frailty has been defined in many ways but most practically, can be evidenced by slowness, weakness, low physical activity, exhaustion and shrinkage (sarcopenia) (62). Life on dialysis is characterised by gradual physical deterioration in several older patients. Physical deficits in the elderly population are seen even in the earlier stages of CKD. A study by Kittiskulnam and colleagues reported that the elderly with CKD were three times more likely to be frail compared to their peers (63). Many are already frail prior to initiation of dialysis and suffer adverse consequences when on dialysis (64).

These consequences include progressive cognitive impairment while on dialysis, especially in the older patient (5). Structural changes in the brain could accompany the cognitive decline, such as white matter damage, brain oedema, microbleeds or changes in brain volume on brain MRI scans in patients who are treated with long-term dialysis

(65). Additionally, older patients on dialysis are likely to suffer increased hospitalisations and healthcare costs, intensive care unit admissions and interventions (66). They are also more likely to die in hospital, rather than at a place of their choice (16,67).

Faced with worsening functional status, cognitive decline and the other components of frailty discussed above, many elderly patients adapt by compromise. They restrict their activities and social roles, giving up the things they do not consider vital anymore. This could be detrimental to them in the long run, as they are assuming the 'sick' role. Therefore, dialysis treatment for ESKD, instead of improving the patient's physical status, potentially leads to increasing dependency and poorer outcomes.

1.2 Value of predicting outcomes on dialysis for older persons

1.2.1 Effects on the decision to start or continue dialysis

In modern renal practice, patients with ESKD who receive regular nephrology follow-up prior to needing dialysis will have a series of discussions with healthcare professionals regarding their choice of treatment pathway. Unfortunately, whether patients are informed about treatment options such as non-dialysis management depends on the unit that they present to (68). Several patients report that they viewed the decision to start dialysis as not a decision or choice - rather, dialysis was the only option, since they understood that the alternative was death. There remains very little understanding of the grim prognosis even with dialysis treatment in this age group. Yet, for a clinical condition with such a poor outcome, renal physicians struggle with

communicating prognosis when they discuss outcomes of dialysis with their patients (20).

The modern healthcare professional is expected to present patients with all the information required for them to arrive at an optimal decision. Patients today expect greater involvement in their healthcare decisions. This was eloquently summarised by the patient statement "Nothing about me without me", presented at the Salzburg seminar session in 1998, and subsequently expounded in the Salzburg statement on Shared Decision-Making articulated in December 2010 (69). Physicians have a responsibility to share important decisions with patients, encourage patients to ask questions and provide accurate information, tailored to patients' needs. These principles have been espoused in guidelines released by various physician associations in renal disease (70–72).

Research into the decision-making process has shown that patients, when compared to the clinicians advising them, may have different or additional considerations as they decide about undertaking treatments such as dialysis (42,73). When counselling older patients and their families regarding dialysis, it is important that the clinician conveys information not only about prognosis and the survival but also about all the other effects that dialysis could have on their lives. This is particularly relevant when considering that patients may regret the decision to start dialysis (45). In addition to the registry data quoted above, several analyses of patient populations have reported poor survival for the elderly, especially if they are already in nursing homes or have multiple illnesses in addition to kidney disease (74,75). There is evidence that older patients often suffer functional impairment in the first few months of starting dialysis (58,76). Many older patients do not anticipate the significant lifestyle changes that dialysis requires.

They tend to view the decision to have dialysis or not as an alternative between life and death, and are often more optimistic about their own prognosis (77).

While there are several reasons as to why physicians struggle with conversations about prognosis in the shared decision-making process (42,78–80), the fact remains that many patients are not fully informed about all the possible outcomes as they consider treatment options. There is a lack of appropriate information to pass on to families and patients. Considering the relatively fewer benefits of dialysis in the older population, the poorer quality of life, the increased hospitalisation episodes and the associated healthcare costs, it is important that older patients make optimal choices about treatment. This will help them avoid the unnecessary suffering that could result from an ill-considered decision to start dialysis treatment.

Additionally, it is quite difficult to predict which older adult will do well on dialysis and who will not. There are no uniform definitions of what 'doing well' means - it is conceivable that healthcare providers and patients have differing expectations. There is insufficient data on quality of life outcomes; we also do not know enough about factors which predict positive outcomes. Anecdotal experience (see Section 1.4) suggests that there are unique personal factors that affect these outcomes, and this is exemplified by the fact that while some older patients deteriorate functionally and psychologically after starting treatment, others appear to thrive and continue in their life-roles. Therefore, a method to predict all these potential outcomes, in addition to mortality, will be useful for clinicians who provide information to a patient considering dialysis treatment for the first time.

1.2.3 Predicting survival

Within the literature, several prognostic instruments have been described which predict both the risk of developing ESKD as well as the risk of mortality once the older patient starts dialysis (81). Estimates exist for 3-, 6- and 12-month survival predictions. Predictive equations can use combinations of demographic variables, presence of comorbidities, biochemical tests, functional assessments or clinical input, such as the response to the surprise question (82,83). Similarly, other equations that predict the risk of renal deterioration to a stage that needs renal replacement therapy (84,85). The challenge is to be able to effectively use the information from these tools in discussions with patients.

Clinical personnel could use prognostic scores to streamline management of patients in a CKD clinic - for instance, to select patients for more intensive follow-up if they run a higher risk of developing ESKD or consider input from palliative care (or other supportive services) if there is a high risk of mortality.

It remains unclear how patients use or understand information gleaned from prognostic tools that predict survival. In general, patients tend to be overly optimistic about their survival probabilities. Patients receiving calculated estimates of survival will need help in understanding how the numbers apply to their individual situation.

However, prognostic information cannot be used in isolation. More likely, prognostic information is one of the many factors that patients and the families consider as they make their decisions regarding treatment. In Chapter 2, the scoping review of literature reports on research into studies of prognosis since 2000 to the present.

1.2.4 Predicting outcomes other than survival

Ideally, patients considering dialysis should have access to predictions of the outcomes other than survival as well. There are no easy means of predicting these outcomes in their entirety.

Several studies have analysed the factors that could influence quality of life. Such factors include those likely to affect mental components of quality of life, such as depression, anxiety, spiritual well-being, age, gender, educational level, dialysis vintage, nutritional status, sleep quality, locus of control / illness perception and coping strategies (avoidance coping strategies were associated with lower QOL scores) (86–90). Physical symptoms have been suggested to directly impact quality of life - this association has been shown in dialysis patients (91). Symptoms are an important contributor to health-related QOL, as postulated in the Ferrans model (30). Therefore, the presence of severe unremitting symptoms could signal a poor quality of life outcome, especially if the symptoms are not relievable by dialysis (e.g., fatigue, depression). Table 4 in Chapter 2 summarises the modifiable and non-modifiable factors that could affect quality of life.

There are few predictors of other outcomes. Fukuma and colleagues, using data from the Dialysis Outcomes and Practice Pattern Study in Japan, created and validated a score to predict functional decline in the elderly after starting dialysis (92). Similarly, other research has shown that being in a nursing home at the start of dialysis is also associated with a high incidence of functional decline (58).

In summary, research that addresses factors affecting outcomes other than mortality is incomplete, and unlikely in its present form to be useful for the discussions regarding dialysis.

1.3 Clinical dilemmas in the selection of therapy for the older patient with end-stage kidney disease

Patients with ESKD tend to approach the decision regarding dialysis treatment as a choice between life and death. However, recent experience has shown us that older patients who are managed with what has been called 'maximal conservative management ' tend to do quite well, both in terms of survival and in terms of quality of life. Direct comparisons between patients managed conservatively and those receiving dialysis have helped identify a subset of elderly patients, often with multiple comorbidities (such as ischemic heart disease or peripheral vascular disease) who derive no benefit from dialysis. These studies have been summarised in Table 2–3.

Individual decision-making continues to remain problematic. The increasing evidence that dialysis treatment may not be beneficial in all patient groups has opened the eyes of clinicians to the need for a more balanced approach, and for decisions to be made with wider ranging discussions. Shared decision-making, with optimal discussions of prognosis are recommended. The focus has to be on arriving at a treatment decision (dialysis or conservative management) that is best suited for the patient. Currently, there are attempts to develop decision support tools for patients having to make this decision. A good example is the Patient Decision Aid developed by the Conservative Kidney Management Care Research Group at the University of Alberta (93). This tool attempts to elicit the preferences of patients with a series of questions and recommends the treatment pathway that is most likely to suit their preferences.

The final decision, though, may be dependent on other, individual factors. Sometimes, these decisions can be arrived at by detailed exploration of patient concerns; physicians

may even modify treatment regimens to suit patient preferences (94). Anecdotal experience suggests that family members may have an important role - not surprisingly, patients that choose dialysis treatment from family compulsions often regret their decision. On other occasions, despite the belief that dialysis may not be in their best interests, older patients may choose to undertake the treatment in order to achieve other goals - for instance, staying alive to support an unwell spouse.

Naturally, patients will turn to their clinicians for advice. It is difficult for the clinician to be completely neutral in this process - i.e., to be a dispassionate provider of information alone (94). Ideally, the clinician, armed with the knowledge of possible outcomes, should be able to elicit in great detail the patient's preferences, and then help the patient to arrive at a decision that is most likely to result in the outcomes that the patient desires.

It is important for the clinician to have adequate knowledge of the outcomes with treatment (mortality as well as other , non-mortality outcomes) in order to have an optimal discussion with her patient. To that end, the purpose of my research was to explore the literature, study the experiences of elderly patients on dialysis and finally arrive at the knowledge of important outcomes and factors that affect these outcomes.

1.4 Researcher's background and context

1.4.1 A nephrologist's role and perspective

In 2011, while working as a consultant nephrologist at a regional Australian hospital, I was struck by the number of older patients who chose not to have dialysis and were subsequently referred back to general practitioners, away from the nephrology department. A survey done in the same period reported that one in seven patients with

advanced kidney disease choose to have non-dialysis, supportive care, otherwise called conservative management (CM) (13). My enquiries into the treatment options for patients that choose not to have dialysis led to the establishment of the renal supportive care service with my hospital. As part of the service, we ran a multidisciplinary clinic that looked after the management of patients that chose CM, including the management of symptoms, psychological support and provision of social or palliative care interventions as required. Anecdotally, several older patients appeared to be satisfied with their choice of CM, with preserved, excellent quality of life until the end-of-life period. This contrasted with many older patients on dialysis. While some of these patients appeared to maintain a satisfactory quality of life, the majority appeared to undergo a spiral of progressive physical deterioration (personal observation). These contrasts awakened my interest into outcomes in the older patient with ESKD, and into whether these outcomes could be predicted.

Further discussions with peers and dialysis nurses, and a brief analysis of the literature revealed that while there were significant amounts of research into survival of patients on dialysis, very little was known about non-survival outcomes such as quality of life. These considerations seemed important to patients and families, especially as they considered whether to undertake dialysis treatment or not. The need to address these gaps in our knowledge was the primary driver for the start of this research project.

1.4.2 The context: treatment pathways for patients with end-stage kidney disease

Tasmania, where this research project was undertaken, is an island-state in Australia which has the distinction of having the oldest population in the country (95,96). Within our dialysis population, about 25% of patients were over the age of 70. Patients in the

community are referred to specialist nephrologists by their general practitioners. Specialists see these patients either in the public hospital system or in private clinics. Once patients have a progressive drop in eGFR, particularly to levels below 20 - 25 ml/min, they are referred to the chronic kidney diseases educator, who is usually an experienced nurse. This educator talks to patients and their families about renal replacement therapy options. Armed with this information, patients return to their nephrologist and discuss their choices before making a decision.

At the time this research project was initiated, there was no systematic approach to documenting their experiences of life on dialysis; there was no structured method to elicit their views about the future, advance care directives or wishes for the end of life. For new elderly patients with ESKD being counselled about renal replacement options, there was no structured method to communicate prognosis (survival and non-survival outcomes). Patients that choose to have dialysis will continue regular follow-up until they start dialysis; they are then seen by the nephrologist once every 6 - 8 weeks. In routine practice, there are few opportunities to elicit information about lived experiences on dialysis.

1.5 Aims of research and anticipated outcomes

Given these circumstances, we were in need of more information about the characteristics that predicted a satisfactory outcome on dialysis, so that patients and families could make informed choices about treatment, thus avoiding needless suffering. A desire to help patients make the best choices and to help them avoid needless suffering was the driving force behind the thesis. The questions I sought to answer were:

- What are the factors influencing survival and other outcomes in older patients with ESKD, whether managed with dialysis or on non-dialysis care - conservative management? (through literature review; Chapter 2)
- What can we learn of the experience of end-stage kidney disease, by studying the physical symptoms and impairment of quality of life? (descriptive, survey-based research studies, Chapter 3)
- In the lived experience of dialysis, what are patients' perceptions of outcomes and factors influencing these perceptions? (qualitative research project, Chapter 4)

The anticipated outcomes from the project were:

- To conduct a scoping review of the literature on the considerations relevant to the discussions about choosing between dialysis and conservative management in the older adult, including:
    - survival and mortality outcomes,
    - quality of life outcomes,
    - learnings to be had from understanding the lived experience of dialysis and
    - other reported information needs of older patients and carers when considering dialysis.
- To describe physical symptoms in the ESKD population and how well they are recognised by treating clinicians (since recognising symptoms is the first step to treating and relieving them)
- To demonstrate the relationship between symptoms and quality of life

- To identify factors associated with satisfactory outcomes for the elderly patient with advanced renal disease, from the patients' perspectives, and
- To create a checklist of factors to be considered during the decision-making processes about treatment for ESKD.

1.5 Thesis Organisation

Chapter 1: Introduction

This section introduces the background to the research, the gaps in knowledge that exist and the questions that the research seeks to answer. It also provides background to the research and researcher. Subsequent chapters are arranged according to the objectives of the thesis.

Chapter 2: Scoping review of the literature

In the second chapter, I present a review of the literature on information that could be used in the discussions regarding treatment in older patients. I used the scoping review format, which seeks to explore the breadth of the research available, rather than grade research quality, so as to produce a comprehensive review. The chapter includes the published protocol for the review, as well as the review itself, in the format that it has been submitted for publication.

While this review summarises what is available in the literature, the subsequent chapters report on research studies done with patients, initially focusing on the experience of dialysis (through the study of symptoms) and subsequently eliciting patient perspectives through qualitative research.

Chapter 3: Quantitative, survey-based research - Symptoms and quality of life

As discussed earlier, symptoms influence the experiences of patients with end-stage kidney disease and affect health-related quality of life and. This chapter reports on the research studies that addressed the symptom burden of patients on dialysis. Studies reported here include descriptions of symptoms and their interaction with quality of life. Poor symptom recognition by clinicians was identified as a prevalent concern, and

my subsequent research investigated the validity of using a patient survey to improve symptom recognition.

Chapter 4: Improving symptom recognition

Following the results in the previous chapter that symptoms were poorly recognised by clinicians, there was a need for a validated method to identify symptoms accurately. This chapter describes a research study where I validated a commonly used symptom survey for patients with end-stage kidney disease, thus paving the way for its widespread adoption and use.

Chapter 5: Qualitative research: living on dialysis

Survey-based research described in earlier chapters allows quantification of pre-selected outcomes such as symptoms. I anticipated that qualitative analysis of conversations with those already on dialysis would yield insights into the outcomes considered important by older patients. This chapter presents the methodology and results of a qualitative study into the experience of dialysis by older individuals. I summarise the patient perspectives on what 'doing well on dialysis' means to them.

Chapter 6: Discussion and Conclusion

In this final chapter, I summarise the findings in the thesis and consider how they relate to the initial objectives. I draw on the lessons learnt from the literature review and our research studies to propose checklists of important factors and possible initiatives for the clinical team to consider as they try to improve outcomes for older patients with ESKD. Next, the possible contributions from this thesis to the existing literature are summarised, followed by a consideration of the implications for routine practice. Areas for future research are discussed, and a final conclusion is offered.

Chapter 2 :
Scoping review of the literature

The consideration of outcomes is crucial to the discussion between clinicians and patients. However, there is a dearth of published information about outcomes in the literature, particularly for older adults, and particularly for outcomes other than mortality. By utilising a scoping review format ,the collection and synthesis of information from varied sources is possible. This information is subsequently summarised and presented in the following tables and graphs.

The protocol for the literature review has been published in the BMJ Open journal (and appended below). Following this the completed scoping review is attached. This review has been submitted for publication. Supplementary material is available online (see Section 2.1.1) and in the appendix (tables A-1 to A-4).

2.1 Older patient considering treatment for advanced renal disease: protocol for a scoping review of the information available for shared decision-making

This protocol has been published as:

Raj R, Ahuja K, Frandsen M, Murtagh FEM, Jose M. Older patient considering treatment for advanced renal disease: Protocol for a scoping review of the information available for shared decision-making. BMJ Open 2016; 6:e013755. doi:10.1136/bmjopen-2016-013755.

A link to the Version of Record on the Publisher's site is attached below:

https://bmjopen.bmj.com/content/6/12/e013755

BMJ Open

Older patient considering treatment for advanced renal disease: protocol for a scoping review of the information available for shared decision-making

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ABSTRACT

Introduction: Older adults constitute the largest group of patients on dialysis in most parts of the world. Management of advanced renal disease in the older adult is complex; treatment outcomes and prognosis can be markedly different from younger patients. Clinical teams caring for such patients are often called on to provide information regarding prognosis and outcomes with treatment—particularly, the comparison between having dialysis treatment versus not having dialysis. These discussions can be difficult for clinicians because they have to contend with incomplete or nascent data regarding prognosis and outcomes in this age group. We aim to summarise the currently available information regarding the prognosis and outcomes of advanced renal disease in the older adult by means of a scoping review of the literature. This article discusses our protocol.

Methods: This scoping review will be undertaken in accordance with the Joanna Briggs Institute's methodology for scoping reviews. A directed search will look for relevant articles in English (within electronic databases and the grey literature), written between 2000 and 2016, which have studied older patients with advanced renal disease (estimated glomerular filtration rate <30 mL/min/1.73 m^2). After screening by two independent reviewers, selected articles will be analysed using a data charting tool. Reporting will include descriptions, analysis of themes using qualitative software and display of information using charts.

Ethics and dissemination: This scoping review will analyse previously collected data, and so does not require ethical approval. Results will be disseminated through academic journals, conferences and seminars. We anticipate that our summary of the currently available knowledge regarding the older adult with advanced renal disease will be a repository of information for clinicians in the field. We expect to identify areas of study that are suited to systematic reviews. Our findings can also be expected to influence guidelines and clinical practice recommendations in the future.

Strengths and limitations of this study

- Previous reviews have not attempted to systematically collect, describe and synthesise all the considerations in making treatment decisions for the older adult with advanced renal disease. This review will collect information across quantitative and qualitative spectra of research, drawing on both published and grey literature. It will also describe data that highlights patient and carer perspectives, both of which are relevant to this life-intrusive illness and its treatment. This widens the sources of information beyond those traditionally used for systematic reviews in the area - this will be a strength of the proposed study.
- Such a wide-ranging review can serve as a useful repository of information for clinicians and others working (or conducting research) in this area; it can suggest areas for further systematic reviews and contribute to generating guidelines.
- The scoping review conducted according to this protocol will address the information available for the shared decision-making process in the older adult. So as to preserve focus, it does not include other aspects of dialysis decision-making, including how this information is presented/received, types of decision-making models, decision science, the impact of health literacy, socioeconomic factors, mental capacity and cognition, cultural/language barriers or resource limitations.
- Studies included will not undergo a formal quality assessment—this is part of the design, as a scoping review attempts to describe all the information available, rather than only select the highest quality of evidence.
- This protocol is for a scoping review that only considers material written in English. Potentially, large populations of the non-English-speaking world may not be represented. Our conclusions may not apply to the different cultural and social environments in these regions.

BACKGROUND

Approximately half of all patients on dialysis in Australia at the end of 2014 were aged 65 and above. Patients aged 65–85 years have the highest incidence (patients per million) of renal replacement therapies.[1] These numbers will conceivably rise in subsequent years as the population on dialysis ages, and as incident patients are added. However, several researchers have suggested that the older patient may not do well on dialysis in terms of quality of life, preservation of independence or survival. Studies suggest that in the presence of severe comorbidities such as frailty or heart disease, there is no survival advantage to being on dialysis.[2] On the contrary, some older patients who choose not to have dialysis enjoy a good quality of life, and may not have a significantly shortened survival in comparison.[2–6]

Several renal units now also offer a distinct, non-dialysis pathway of care for patients opting *not* to have dialysis treatment for end-stage renal disease—thus providing another valid and available treatment choice for these patients.[7] This pathway may be called the 'conservative', 'supportive' or 'renal palliative' care pathway.

Principles of holistic care in the management of the older patient are widely applicable—including detailed symptom management, advance care planning, functional assessment and appropriate support, and targeted measures to improve quality of life. However, uncertainty exists regarding the benefits of dialysis therapy in the older adult. Predicting which older patient will do well on dialysis is quite difficult.

Nephrologists and other members of the renal team are often central to the discussions around treatment choices for advanced renal impairment. National organisations, such as the Australia New Zealand Society of Nephrology or the Renal Physicians Association in the USA, suggest a process of shared decision-making for patients considering dialysis.[8 9] Shared decision-making is defined as 'a process by which a healthcare choice is made by the patient (or significant others, or both) together with one or more healthcare professionals'.[9] Clinical practice recommendations in this area suggest that 'nephrologists do not shy away from these discussions'—rather, they suggest, treating teams ought to have 'realistic discussions' with patients about survival and quality of life with and without dialysis treatment.[8 9]

The provision of information is an important component of shared decision-making, as exemplified in several popular models of the process. For instance, in the Interprofessional Shared Decision-Making Model,[10] 'information exchange' is an integral part of the process. Similarly, in the model suggested by Elwyn and colleagues,[11] which consists of a 3-step shared decision-making model for clinical practice—'choice talk, option talk and decision talk', provision of information is an integral part of discussions about options and choice. Accurate information is central to shared decision-making, as it 'rests upon knowing and understanding the best available evidence on the risks and benefits across all available options, while ensuring that the patient's values are taken into account'.[10] However, providing or accessing such information often proves difficult for the clinician, as sufficient, comprehensive information is not readily available.

Comprehensive conservative treatment for renal impairment that does not include dialysis is an actively evolving paradigm of care, with few practices backed by high-quality evidence, making standardisation difficult. Additionally, most such care is provided in heterogeneous settings, by different professionals (eg, multidisciplinary clinics). Such factors make head-to-head comparisons of the two modalities (dialysis vs non-dialysis) cumbersome, limiting the information available for a discussion comparing the two pathways.

There are other practical difficulties. Studies have shown significant variability in how different doctors make decisions about recommending dialysis.[12 13] Estimates of prognosis made by doctors are likely to be inaccurate. Age and non-renal factors may not always receive consideration. Factors such as comorbidities, frailty, mental status, dependency for transfers and residence in a nursing home can all impact on the prognosis on dialysis, but it is difficult to consider these variables systematically in making decisions. Efforts to construct prognostic indices for the older adult considering dialysis have met with limited acceptance. Often, these indices document prognosis for patients already on dialysis, or they do not consider non-renal factors. Not surprisingly, patients may consider non-medical factors important to their decision—such as the number of hospital visits required, or the restrictions on travel.[14 15] Clinicians may not be aware of such research into patient and caregiver preferences for treatment or end-of-life choices.

In summary, there are uncertainties and gaps in knowledge when renal teams are called on to provide appropriate comparisons between treatment with or without dialysis in the older patient with advanced renal disease. The life-sustaining nature of dialysis presents difficulties in the design of a randomised trial comparing dialysis treatment with treatment without dialysis in this population. Given this scenario, the scoping review methodology, extending across quantitative and qualitative research domains, appears well suited as a first step in detailing the breadth of information available in this particular area at present. From the information gathered, we anticipate that the need for future systematic reviews in particular areas will be identified.

METHODS AND ANALYSIS

(Please see figure 1 for a flow chart detailing the major steps in the scoping review.)

This scoping review will be undertaken in accordance with the Joanna Briggs Institute's methodology for scoping reviews.[16]

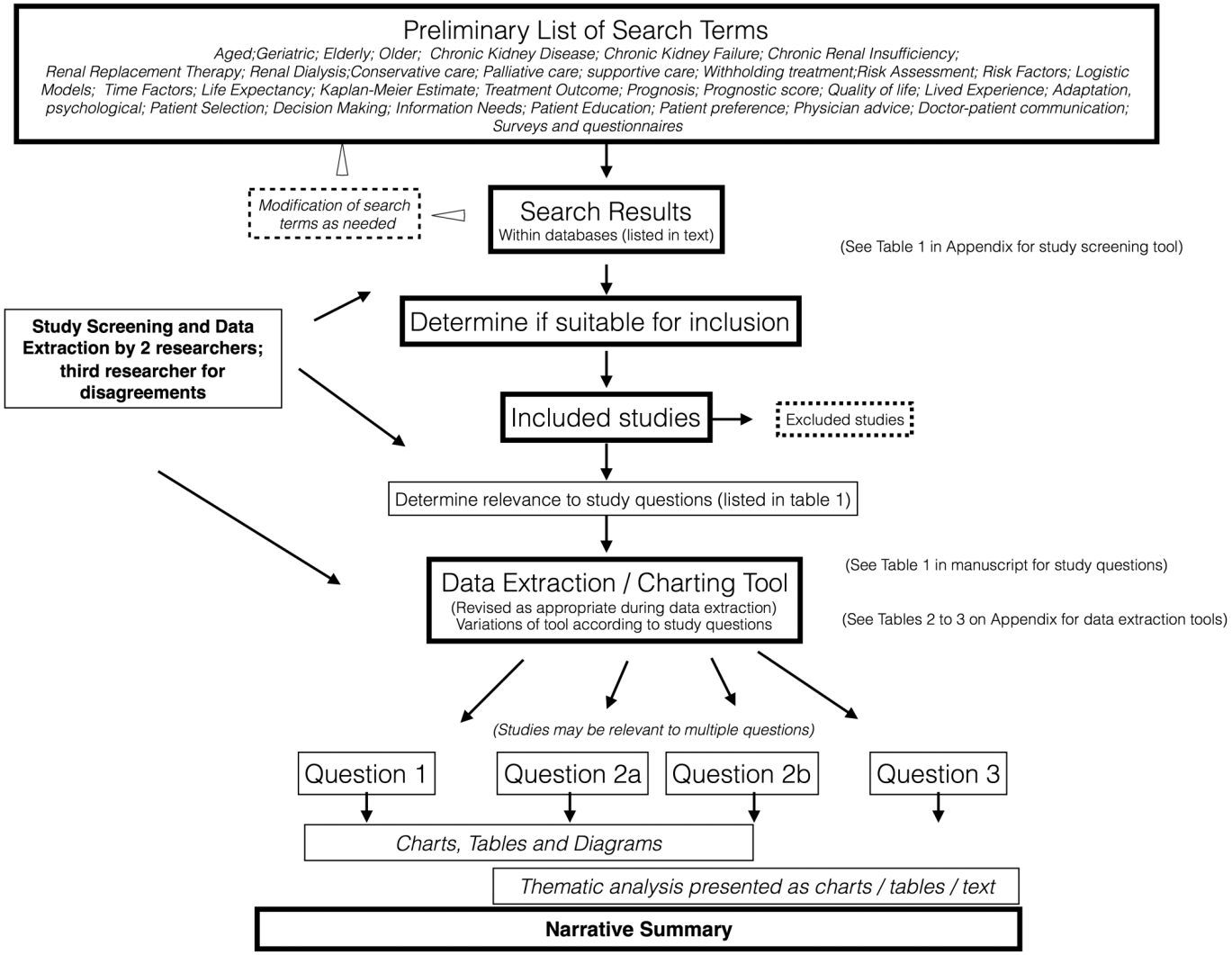

Figure 1 Flow chart of proposed scoping review.

From readings of published literature and clinical guidelines/recommendations, we anticipated, empirically, that five broad categories of information are likely to be relevant to the discussions around treatment options for the older adult, as follows:

- information about prognosis/survival in older patients with advanced renal disease managed either with or without dialysis treatment;
- information about quality of life in older patients with advanced renal disease managed either with or without dialysis treatment;
- information describing the lived experiences of the older adult with advanced renal disease;
- information on the factors important to older patients and their careers as they make treatment choices around advanced renal disease;
- other factors, not included above.

A preliminary search of the literature in The Cochrane Library, JBI Database of Systematic Reviews and Implementation Reports, TRIP database and Prospero failed to identify a scoping review that summarises the entire range of considerations discussed above.

Operational definitions

Older adult

Different chronological ages have been used in the literature to define the term 'older adult' or 'elderly'.[17] In order to include all relevant data, we will include studies where the population studied has been described by primary researchers as 'elderly', 'geriatric' or 'older adult' without specifying beforehand an age cut-off to define the older adult. In the summaries created, we will mention the ages of patients included under this term in relevant studies.

Patients with advanced renal disease

This is defined as patient populations in any of the following categories:

- having established (>3 months) renal impairment with an estimated glomerular filtration rate (eGFR) of <30 mL/min/1.73 m^2;
- described as having 'advanced renal disease' by the primary researchers;
- receiving education regarding renal replacement therapies;

- on dialysis;
- on non-dialysis, supportive or conservative care.

Carers

Includes all individuals involved in directly caring for the patient, whether associated through family, friendship or marriage.

Clinicians

Clinicians include doctors, nurses and allied healthcare staff directly involved in the medical care of, and the shared decision-making process with, patients and carers.

Dialysis treatment

Dialysis treatment involves renal dialysis, including all forms of haemodialysis and peritoneal dialysis, including in-centre, home-based, assisted or self-care approaches.

Conservative care

Conservative care includes care given to patients with advanced renal disease who have decided not to undergo dialysis treatment, described as 'non-dialysis', 'supportive', 'conservative' or 'palliative' renal care.

Objectives

The objective of this review is to identify and summarise the nature and scope of information available for consideration when discussing treatment options for advanced renal disease with an older patient.

The study aims to synthesise information from quantitative and qualitative literature, so as to

- provide a coherent summary for clinicians;
- explore the need for future comprehensive systematic reviews on the subject.

Review questions

The questions for this scoping review are as follows (summarised in box 1):

- What information is available to be used in the shared decision-making process for the older adult considering treatment options for advanced renal disease? Specifically, the details examined are:
  - markers of prognosis (survival) in the older patient with advanced renal disease;
  - factors influencing quality of life in the older patient with advanced renal disease;
  - reports of lived experiences of older adults undergoing treatment (with or without dialysis) for advanced renal disease.
- What do we know about the information needs of older adults and their carers as they consider treatment options for advanced renal disease?

Box 1 Review questions

1. What are the factors affecting prognosis and survival in the older patient with advanced renal disease either choosing to have dialysis treatment, or choosing to have conservative care without dialysis?
2. (A) What factors influence the quality of life in the older patient being treated for advanced renal disease?
(B) What information is available regarding the lived experiences of older adults treated for advanced renal disease?
3. What is known about the information needs of older adults and their carers considering treatment options for advanced renal disease?

Inclusion criteria

Study selection

This scoping review will consider, for all questions, articles that address the older adult with advanced renal disease, their carers or the clinicians involved in their care, regardless of sex, region, diagnoses or comorbidities (see figure 1). Articles from peer-reviewed scientific literature as well as those from grey literature will be considered (details below).

Concept

The core concept of this scoping review is to provide a summary of the breadth of information relevant to discussions and decision-making in the older adult with advanced renal disease who is considering treatment options. The primary focus is on the information that is likely to be of value in choosing whether to have dialysis (any type of dialysis) or not. With regard to the specific questions articulated above,

- For question 1, studies that report on prognosis, prognostic indices, survival and mortality in the population described will be considered for inclusion.
- For question 2 (A), studies that describe quality of life data in this population, either in isolation or in relationship to other variables, including descriptive/observational and interventional studies will be included.
- For question 2 (B), studies that describe the lived experience of these patients and their carers will be considered.
- For question 3, studies that have described the information needs of older adults and their carers around the decision-making process in advanced renal disease will be considered.

Context

This scoping review will consider articles pertaining to the older adult in inpatient, outpatient, home or residential care facility settings.

Sources: study types

(Please see online supplementary table S1 for a draft version of the initial appraisal tool.)

This scoping review will consider quantitative and qualitative study designs, including:

- Experimental and quasi-experimental studies (randomised and non-randomised controlled trials), before and after studies and interrupted time-series studies.
- Analytical and descriptive observational studies including prospective and retrospective cohort studies, case–control and cross-sectional studies, case series and case reports.
- Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description and action research.
- We will also include searches of the grey literature (see description of databases below).
- Textbook chapters and opinion papers will also be considered for inclusion.
- We will also include recommendations made by national bodies involved in setting standards and providing guidelines for renal care.

Studies published from January 2000 to October 2016 will be included so as to reflect the increasing number of older patients on dialysis, the changing attitudes to the treatment of older adults in recent years and the establishment of conservative care without dialysis as a valid treatment option. Only studies with abstracts published in English will be included in the initial screening process.

Exclusion criteria

- research that does not address older adults (see operational definition above) as a main or subpopulation of interest;
- research that exclusively addresses patients with an eGFR >30 mL/min/1.73 m^2;
- studies in languages other than English.

Search strategy

An initial limited search of MEDLINE, Scopus, Embase, PsycINFO, CINAHL and Cochrane Library databases has been undertaken to identify articles on this topic. Analysis of the words contained in the titles, abstracts and index terms used to describe these articles was used to develop an initial list of search terms and keywords, as follows:

- humans; aged; geriatric; elderly; older;
- chronic kidney disease; chronic kidney failure; chronic renal insufficiency; renal replacement therapy; renal dialysis;
- conservative care; palliative care; supportive care; withholding treatment;
- risk assessment; risk factors; logistic models;
- time factors; life expectancy; Kaplan-Meier estimate;
- treatment outcome; prognosis; prognostic score; quality of life; lived experience; adaptation, psychological;
- patient selection; decision-making; information needs; patient preference; patient education; physician advice; doctor–patient communication; surveys and questionnaires.

The keywords/search terms will be appropriately used for each database. As studies are being considered, their reference lists will be screened for additional studies.

Databases searched

The following databases will be searched: PubMed PsycINFO, CINAHL, Embase, Scopus, Mednar, Turning research into practice, NTIS, ProQuest Dissertations and Theses, Google Scholar and Current Contents.

The search for articles in the grey literature will include electronic sources including OpenSIGLE, Healthcare Management Information Consortium (HMIC) Database, National Technical Information Service (NTIS), PsycEXTRA, BIOSIS Databases, Open Grey, Trove, EThOS, OATD.org and OpenThesis.

The search for guidelines will include searches at the National Guideline Clearinghouse, http://www.cari.org, http://www.kdigo.org, the National Kidney Foundation (NKF-DOQI), Kidney Health Australia, the Renal Physicians Association, ERA-EDTA and national specialty organisations (USA, UK, Australia, European).

Data extraction

Data will be extracted from papers included in the scoping review using the draft data extraction tools listed in online supplementary tables S2–5 by two independent reviewers, and entered into spreadsheets. The data extracted will include specific details about the populations, concept, context, and study methods of significance to the scoping review question and specific objectives. Any disagreements that arise between the reviewers will be resolved through discussion, or with opinion from a third reviewer. When required, authors of papers will be contacted if possible to request missing or additional data. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included study. Modifications will be detailed in the full scoping review report.

Data mapping/analysis/synthesis and presentation of the results

The extracted data will be presented in diagrammatic or tabular form that is relevant to the objectives and scope of this scoping review. We will summarise the information separately for each question that forms the basis of this scoping review.

For questions 1 and 2 (A), we will present in tabular form the various factors reported to influence prognosis/survival and quality of life, respectively, detailing the number of studies for each such factor, the number of patients studied, the settings, and provide comment about the generalisability of the findings.

For information addressing question 2 (B)—'the lived experience of dialysis'; and question 3—'information needs for the shared decision-making process', the findings will be displayed in tabular and diagrammatic form,

and in addition, we will use N-Vivo qualitative research software (QSR International, Australia) to synthesise the various themes identified.

A narrative summary will accompany the tabulated and/or charted results and will describe how the results relate to the primary questions around shared decision-making in the older patient with advanced renal disease. We anticipate that the identification of information needs will also guide the organisation of the information collected.

Ethics and dissemination

Ethical approval for the conduct of this study will not be required as this research only includes analysis of previously collected data. Results will be disseminated through academic journals, conferences and seminars. We will attempt to publish our findings in international open-access, peer-reviewed medical journals so that they are freely available.

CONCLUSION

The older patient with renal disease is different from younger counterparts on several counts—comorbidity burden, disease progression, survival, outcomes with therapy and considerations that influence quality of life. A 'one-size-fits-all' approach to counselling and prescribing renal replacement therapy cannot be recommended. The scoping review proposed will attempt to synthesise the disparate pieces of information available, and to be a resource for clinicians advising such older patients.

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Contributors RR is the primary and corresponding author and was responsible for initial discussion and the first and all subsequent drafts. KDKA, MF and MJ were involved in the initial discussion and design of the study protocol. They contributed to the design of the work, and revised the drafts critically for content. All four authors approved the final version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement RR, MF, KDKA and MJ are the four authors of this scoping review protocol. The data used for creating this protocol were obtained jointly by the authors from readings of published literature. These data continue to be freely available to the authors via the library access provided by the University of Tasmania. The scoping review will collect articles to be considered for inclusion in the review. All bibliographic lists, full-text articles, data extraction tables, summary reports and the final written article will be stored on servers of the University of Tasmania, protected by user id/password access for all four researchers. Thus, all four researchers will have free and continued access to all the data collected and synthesised for this protocol development and the ensuing scoping review.

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2.1.1 Scoping review protocol: Supplementary material.

Drafts of the initial appraisal tool and the data extraction tool for articles addressing each of the questions in the scoping review have been published as supplementary online material, and are available at the following link:

https://bit.ly/2WuAusM

2.2. Shared decision-making in older adults with advanced renal disease: a scoping review of the information available

The following is the final proof of the article submitted for publication as:

Raj R, Thiruvengadam S, Ahuja K, Frandsen M, Jose M. Shared decision-making in older adults with advanced renal disease: a scoping review of the information available

2.2.1 Abstract

Introduction

Older adults may not receive the same benefits from dialysis as their younger counterparts. Clinicians often have to provide information regarding prognosis and outcomes with or without dialysis treatment. We performed a scoping review to summarise the information available for shared decision-making with older patients considering dialysis and to identify areas for further study.

Methods

A directed search was undertaken for articles in English (within electronic databases and the grey literature), published between 2000 and August 2018, studying older adults with advanced renal disease (eGFR ≤30 ml/min/1.73 m^2). Articles were grouped by topic into those describing prognosis, factors influencing quality of life, lived experience of dialysis or information needs of patients. Research comparing dialysis modalities was excluded.

Results

Two independent reviewers screened 15,445 initial results and selected 248 for final analysis. Original research focused primarily on prognosis or described lived experience; comparatively fewer addressed factors affecting quality of life or patients' information needs. We summarised prognostic instruments and factors affecting quality of life; reported comparisons of conservative care to dialysis, and suggested improvements to provision of patient-centred information. We propose areas for future research.

Conclusion

Increasing age and comorbidities reduce survival and other health benefits from dialysis for the elderly when compared to conservative management. Although existing tools can predict survival, patients desire more information and greater involvement in decision-making. Research needs to address the provision of knowledge more relevant to patients, and the factors that improve patient-centric outcomes beyond mere survival.

2.2.2 Introduction

Physicians are uncomfortable about communicating prognosis to seriously ill patients (97,98). This is also true for nephrologists looking after patients with advanced renal disease (20,43,80,99,100). There is evidence to suggest that patients receive insufficient information, or are unrealistically optimistic about their prognosis (68,77). Patients often wish they had received more information prior to commencing dialysis. For instance, they expect their doctors to provide them information about prognosis even without being prompted to do so (101,102). These descriptions, on both sides of the physician-patient relationship, become even more important when considering shared decision-making in elderly patients with advanced renal failure (103).

In older patients who develop advanced kidney disease, the rate of progression of kidney disease may not be as rapid as their younger counterparts (104). Additionally, in older patients who do progress to end-stage renal failure, treatment with dialysis, which is the default option, may not always lead to better outcomes or improve quality of life (12,17) . With this in mind, several nephrology centres across the world and in Australia now recommend or offer a dedicated program of renal conservative management (that is, holistic patient management that does not include dialysis or transplantation) (11,13,14,105–108). The current dilemma, for patients and physicians alike, is in deciding which among these two options – dialysis or conservative management – is ideal for an individual patient (109).

Professional nephrology associations call upon the community to ensure that decisions regarding dialysis, especially in the older, sicker adults, be made according to the principles of patient-focused, shared decision-making (71,72). Open, transparent and complete sharing of information, particularly with regards to prognosis and quality of life, with dialysis treatment or otherwise, is an important part of this process. However,

physicians may be handicapped by the lack of appropriate information regarding outcomes of the various forms of treatment in the older population (110). Different prognostic instruments that predict renal worsening or survival exist, but while some are rigorously developed and validated, others may not be accurate or ideally developed; similarly, instruments validated in one population may not be automatically transferable to another population. (84,111–113) . There is a perceived paucity of information on outcomes other than survival – such as functional status or quality of life – that are important to patients.

The numbers of older patients on dialysis are increasing (80). The information required to provide appropriate advice is spread across multiple domains, and not easily available in a consolidated form. These characteristics are well addressed by the scoping review format, which reports on the breadth of information available in the area, intending to describe the field and uncover gaps in the literature, if any. We therefore undertook a scoping review of the information available to the clinician for use in the process of shared decision-making with the older patient considering the choice between dialysis or conservative management. The objectives, inclusion criteria and methods for this scoping review were specified in a previously published protocol (114). In brief, this scoping review sought to address the following questions in the older patient with advanced renal disease:

- What are the factors affecting prognosis and survival (with dialysis treatment, or with conservative management not including dialysis)?
- Which factors influence the quality of life?
- What information is available regarding the lived experiences with the various treatment pathways?

- What is known about the information needs of this population as they consider treatment options?

2.2.3 Methods

The scoping review adhered to the PRISMA-ScR checklist for scoping review conduct and reporting, as detailed in the table provided in supplementary material (115).

Objectives and research questions

The objective of this review was to identify and summarise the nature and scope of information available for consideration when discussing treatment options for advanced renal disease with an older patient.

The study aimed to synthesise information from quantitative and qualitative literature, with reference to the research questions listed above, so as to:

- Provide a coherent summary for clinicians, and
- Explore areas for future research.

Inclusion criteria

The scoping review included articles that addressed older adults with advanced renal disease, and focused specifically on survival/mortality, factors affecting prognosis or quality-of-life, descriptions of the lived experience of treatment (on dialysis or conservative management) or descriptions of the information needs of older adults. These four areas were developed by consensus between the authors after considering the areas of relevance to the dialysis decision.

In order to capture all relevant data, we included all studies where the population studied was described by primary researchers using terms such as 'elderly', 'aged', 'geriatric' or 'older', without pre-specifying an age cut-off to define the older adult.

Advanced renal disease was defined as an estimated glomerular filtration rate (eGFR) ≤ 30 ml/min/1.73m^2.

We included articles from the time period of January 2000 to August 2018. This time period was chosen so as to reflect the increasing number of older patients on dialysis, the changing attitudes to the treatment of older adults in recent years and the establishment of conservative care without dialysis as a valid treatment option. All forms of research, including quantitative and qualitative methods, and articles that were published in peer- reviewed literature as well as the "grey" literature were included. The focus was on information that was likely to be of value in choosing whether to have dialysis (any type of dialysis) or not. Only articles written in English were included (as we had limited translation resources).

Exclusion criteria

- research that did not address older adults (see operational definition above) as the main population or as a subpopulation of interest,
- research that primarily focused on those with an eGFR > 30 mL/min/1.73 m^2),
- research exclusively comparing variations of dialysis treatment modalities or transplantation with each other,
- research describing the effects of interventions other than dialysis, or
- research with reports in languages other than English.

Search methodology

Databases searched included: PubMed, Embase, PsycINFO, CINAHL, EbscoHost, Mednar, Cochrane, TRIP databases, and Web of Science for peer-reviewed research, and OpenSIGLE, Open Grey, Trove, EThOS, OATD.org and OpenThesis for grey literature.

Websites of national specialty societies and clinical guideline collections were also searched. Searched terms included those relevant for elderly patients, chronic kidney disease, dialysis, conservative management, prognosis, survival, quality of life, lived experiences and information needs. These terms were adapted to suit searches in individual databases; examples of search terms are provided in the appendix as supplementary material.

Initial screening of articles was undertaken by 2 researchers (RR and ST) working independently, using the web-based Rayyan QCRI software (Qatar Computer Research Institute and Qatar Foundation, Qatar) (116). Charting of included studies and the extraction of relevant information was done using FileMakerPro16© (FileMaker Inc., California, USA) and Microsoft Excel© software (Microsoft Corporation, Washington, USA). Separate data extraction forms and charting sheets were used for the four different research questions, as shown in the published protocol (114). For included articles, the following data was extracted: primary author, year of publication, type of research, modality of treatment studied, population, focus of research, and main findings. Forms used for final data extraction are provided as supplementary material.

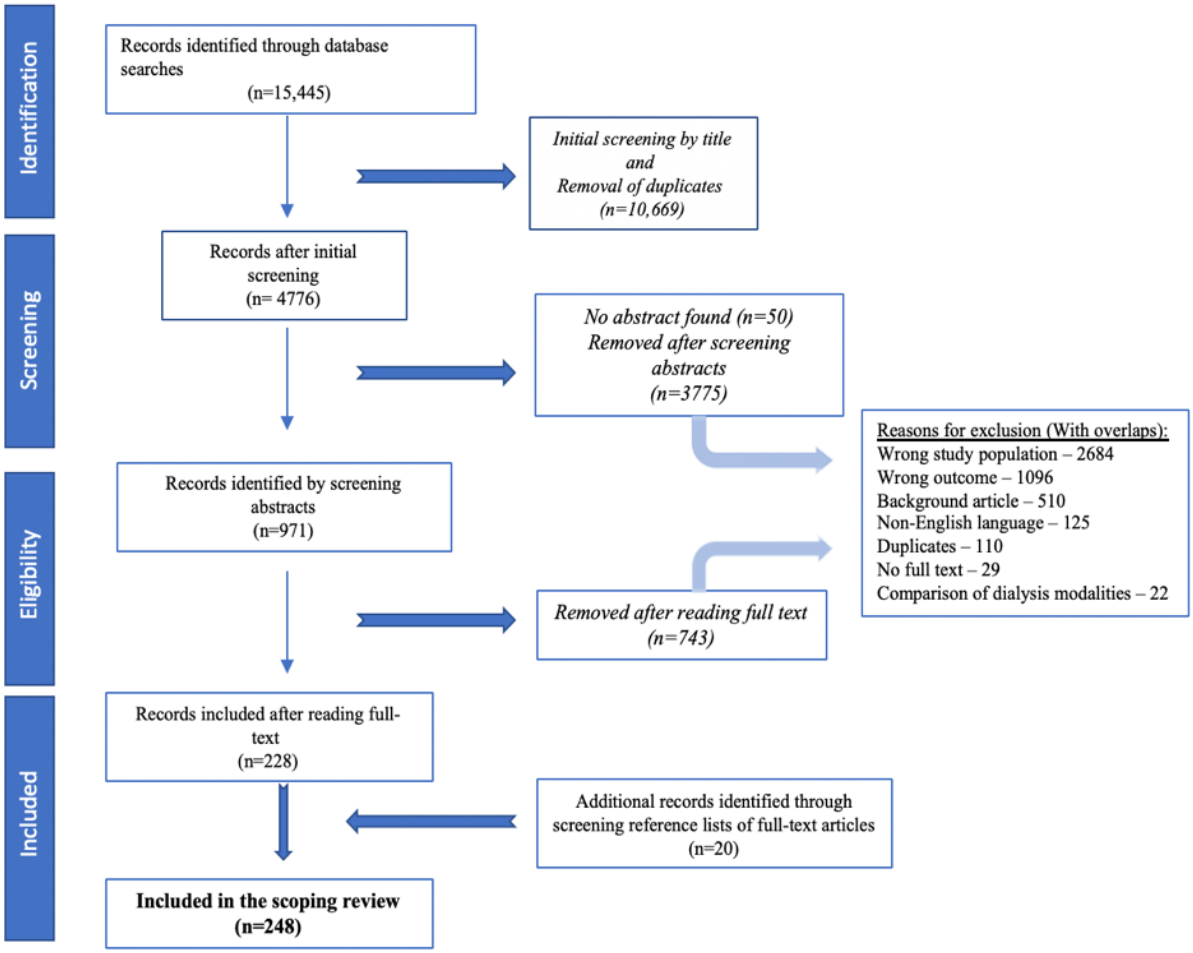

Figure 2-1 Prisma Flowchart for Study Inclusion (29)

2.2.4 Results

Figure 1 shows the flowchart summarising the selection of studies to be included in this scoping review, and the reasons for exclusion. All 15,445 articles identified in databases were imported into the reference management software as detailed. Subsequent screening of titles and removal of duplicates provided 4776 articles for review with abstracts. These articles were divided into groups depending on the questions of the survey; and 971 articles for used for full text review. Cohen's kappa for inter-rater agreement between the two reviewers screening the articles for inclusion was 0.54, suggesting "moderate" agreement (117). All conflicts were discussed with remaining authors and resolved. Finally, after perusal of full text, 228 articles were included, along with 20 articles found by hand-searching reference lists of included articles, making up 248 articles selected for analysis. This included three theses obtained from screening of the grey literature.

The majority of included articles have primary authors resident in the English-speaking countries - USA, UK, Canada and Australia. Japan, France, Taiwan and Holland were the other significant contributors (Figure 2-2). A greater proportion of research literature was written in the previous five years (2012-2017); the number of articles on older patients with renal failure showed an increasing trend in recent years.

Overall, half the included articles refer to patients on haemodialysis (HD) exclusively; 18% were studies on patients not on dialysis and 5% included all elderly patients with end-stage kidney disease (ESKD), regardless of treatment choice. Peritoneal dialysis (PD) patients alone contributed to 8% of studies while 17% included patients undergoing both peritoneal and hemodialysis (Figure 2-3).

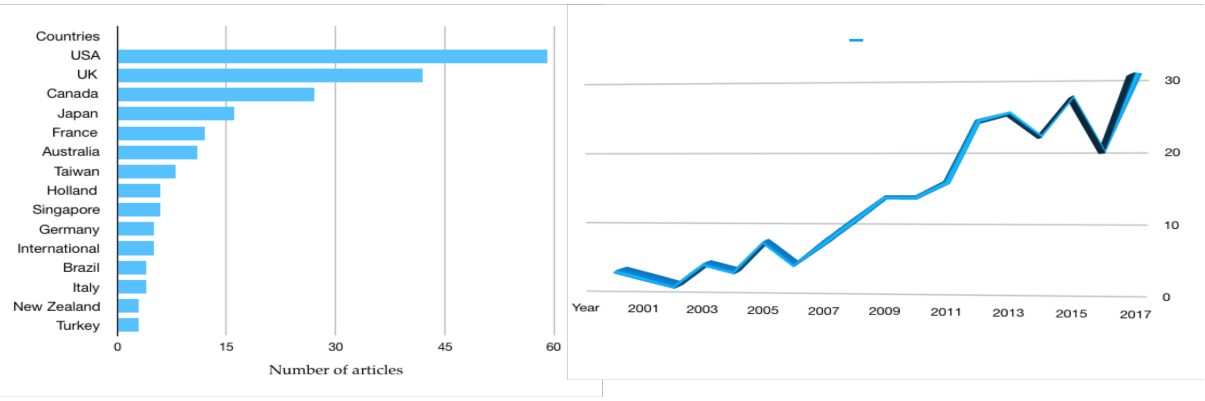

Figure 2-2: Countries of origin and years of publication of included articles

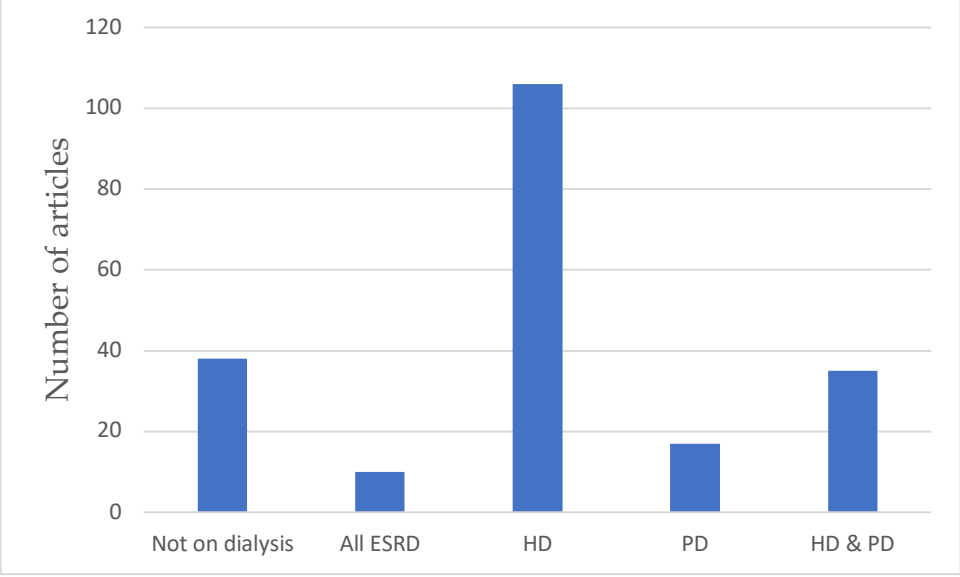

Figure 2-3: Modality of treatment in included studies

(see text for abbreviations)

For purposes of analysis, the included studies were analysed in groups, according to the research questions for the review detailed above (prognosis, quality of life, lived experiences and information needs respectively). The following Section on results is also presented according to these questions.

Characteristics of studies describing prognosis

A hundred and twelve articles that specifically focused on the prognosis of the elderly patient with advanced renal failure were included in the review. Thirty-four were single centre studies; 28 involved patients in multiple centres, while 24 studies, often with participant numbers in excess of 1000, were conducted as registry-based research. Sixty-six studies (61.8%) were retrospective studies (including 20 out of the 24 registry-based studies). Studies that only included patients on haemodialysis predominated (39 studies).

Content and scope of studies describing prognosis

Mortality/survival was the commonest prognostic outcome of interest. Other outcomes were also studied, usually in addition to mortality included quality-of-life outcomes, time to renal replacement therapy/end-stage renal failure, hospitalisation, functional or nutritional status (see supplementary material for details).

Researchers considered several different variables for inclusion as prognostic markers (Table 2-1). The stated aim in several papers was to use easily available, clinical indicators to predict prognosis. Most commonly, researchers used a combination of variables - clinical, laboratory, demographic or instrument-based data to derive prognosis. These variables could be grouped into sociodemographic variables (including age, nursing home residence), comorbidities, functional status, nutritional parameters, aspects of nephrology or dialysis care and biochemical variables.

Table 2-1: Prognostic factors considered in various studies

Sociodemographic	
Age	Comorbidities/ Organ function
Gender	Number of comorbidities
Race	Diabetes
Institutionalisation (e.g., nursing home)	Hypertension
	Dementia
Nephrology Care	Depression
Mode of treatment (Dialysis Vs Non-Dialysis care)	Visual impairment
	Residual urine
Length of renal follow-up	Ejection fraction
Hospitalisations	
Elective vs unplanned start	
Related to dialysis	
Elective vs unplanned start	Biochemical tests
Dialysis access	GFR, from serum creatinine
Adequacy	Rate of fall of GFR
Length of session	Urine Creatinine, Proteinuria
Dialysis vintage	Albumin
	Haemoglobin
Functional status	Calcium
Self-rated health	Phosphate
Frailty	Parathyroid hormone
Mobility	HbA1c
Falls	Cholesterol
Dependence	C-reactive protein
Activities of daily living	Testosterone
Bedridden status	Plasma pro-ANP
	P-cresyl sulphate
Body composition	Indole sulphate
Sarcopenia	
Muscle mass and fat	

*Studied individually, or as part of other indices.

A common method was to use a combination of variables in order to predict prognosis. While some studies investigated particular combinations of variables in single cohorts, others reported inception and validation cohorts, presenting the combination of variables as an index or prognostic score. Some of these scores were developed specifically in patients with renal failure, while others were adaptations of prognostic tools used in the general population. Table 2-2 and 2-3 describe such indices that were developed exclusively in the elderly or use age as a variable in the index to derive prognosis (therefore making them suitable for use in the elderly population).

Table 2-2: Prognostic Indices developed in the Pre-dialysis Renal Population

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
Data from patients not yet on renal replacement therapy (RRT) or those receiving conservative, non-dialysis care					
Bansal et al, 2005 (118)	Predictive model (9 variables: including age, demographics, eGFR, urine albumin, comorbidities and smoking history)	5-year **mortality** in community - dwelling adults with chronic kidney disease (CKD) in two different study populations	n=828, Age 80±5.6 eGFR: 47(±11); from the Cardiovascular Health Study	n=789; Age 74±2.8 eGFR: 50±9 from the Health, Ageing, and Body Composition Study	c-statistic*: IC: 0.72 (0.68-0.74) VC: 0.69 (0.64-0.74)
Landray et al, 2010 (119)	Prognostic models for risk of ESKD (4 variables: creatinine, phosphate, urinary albumin-creatinine ratio [UACR], female gender) and risk of death (4 variables: age,	**Risk of ESKD** and risk of **mortality** in patients with CKD stages 3-5 in populations from 2 separate cohorts in Birmingham and East Kent, UK	n= 382 Age: 61.5±14.3 eGFR: 21.8±10.7 Follow up: 4.1 years ESKD rate: 12.1% per annum Mortality rate overall: 6.5% per annum; rates worse	n= 213 Age: 65.1 ± 13.5 eGFR: 21.6 ± 13.6 ESKD rate: 12.1% per annum Mortality rate overall: 9.2% per annum (no UACR in Kent; all	c-statistic: Prediction of ESKD: IC: 0.873 (0.836-0.909) VC: 0.91 (0.87-0.96) Prediction of mortality: IC: 0.82 (0.774-0.866)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
	NT-pro BNP, troponin-T and cigarette smoking		with more advanced CKD	participants assigned 350 mg/g)	VC: 0.82 (0.75-0.89)
Tangri et al, 2011 (84)	Kidney Failure Risk Equation; (Most accurate model contains age, sex, eGFR, albuminuria, and serum calcium, phosphate, albumin and bicarbonate)	1-, 3-, and 5-year **risk of ESKD** in patients with eGFR 10 - 59 in 2 Canadian populations	n=3449; Age 70±14 eGFR: 36±13 24% incidence of kidney failure	n=4942; Age 69±14; eGFR: 31± 1.1; 11% incidence of kidney failure; Patient cohort from different area in Canada	c-statistic*: IC: 0.917 (0.901-0.933) VC: 0.841 (0.825-0.857) (Also passed calibration and other estimates of accuracy)
Drawz et al, 2013 (85)	Veteran Affairs Risk Score (6 variables: age, CHF, systolic BP, eGFR, potassium and albumin)	1-year **risk of ESKD** in adults > 65, with eGFR <30	n=1866 Age: 77.5±6.4; eGFR: 25±4.3 95% were male	n=819; Age: 78.16.4 eGFR: 24.9±4.3 97.8% were male. (from a different health jurisdiction)	c-statistic*: IC: 0.854 VC: 0.823
Chua et al, 2014 (120)	**UREA5** score (**UR**ate, **E**jection fraction, **A**ge, **A**rteriopathy - peripheral, **A**rteriopathy - CVA, **A**lbumin, **A**LP)	1-year **mortality** in incident dialysis patients (HD and PD); retrospective study; based on parameters **prior to dialysis initiation**	n=983 Age: 60±13 eGFR: 6.6 (4.8-9.2) 22% > 70 years	Not described	c-statistic*: IC: 0.74
Wick et al, 2017 (121)	Predictive model (7 variables, including: Age>80, eGFR, comorbidities, hospitalisation)	6-month **mortality** after dialysis initiation studied in patients > 65 in a single Canadian Centre based on values **prior to initiation**	n= 2199 Age: 75.2±6.5 eGFR: < 15 in 81.2% Patients starting dialysis between 2003-2012 in a regional	No VC	c-statistic*: IC: 0.72 (Well calibrated)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
			registry in Canada. 52% had congestive heart failure, 58% diabetes		
Schroeder et al, 2017 (122)	Predictive model: (8 variables including: Age, gender, eGFR, haemoglobin, proteinuria, systolic BP, antihypertensive medication use and diabetes)	5-year **risk of needing RRT**, in a retrospective cohort of patients with CKD **not yet on RRT** who were members of a US managed care consortium	n = 22,460 Age: 74.6±10.1 eGFR: 46.8±10.1 All those with a persistent stage 3 or 4 CKD	n= 16,553 Age: 74.7±9.0 eGFR: 47.5±9.8 All those with CKD stage 3 or 4 from a geographically different branch of the managed health program	c-statistic*: IC: 0.96 (0.95-0.97) VC: 0.95 (0.94-0.97) R^2 value: IC: 79.7 (78.6-80.8) VC: 81.2 (17.6-82.6)

Table 2-3: Prognostic Indices applicable to the incident population on dialysis

Author& Year	**Index**	**Description**	**Inception Cohort (IC)**	**Validation Cohort (VC)**	**Accuracy / Results****
Data from the incident period for patients on haemodialysis or peritoneal dialysis (HD and PD)					
Couchoud et al, 2009 (123)	Predictive model (9 variables – including body mass index, comorbidities, functional status and unplanned dialysis initiation)	6-month **mortality** in older adults starting dialysis between 2002 and 2006 based on French REIN registry data **at the time** of initiation	n=2500; Age>75; eGFR: n.a. Randomly chosen from the registry.	n=1642; Age>75; eGFR: n.a. Randomly chosen from registry; similar overall characteristics to inception cohort	c-statistic*: IC: n.a VC: 0.7 (Well calibrated; Good transportability to 3 months and 12 months)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
Wagner et al, 2011 (124)	Predictive model (13 variables in final model including age, demographics, comorbidities, primary kidney disease, treatment modality and biochemistry,)	All-cause **mortality**, after the first 3 months, in adults >18, in the UK Renal Registry, **incident to dialysis** in the period 2002-2004; majority on haemodialysis)	n= 3631 Age: 64 (49-73) Creatinine: 7.2 (5.6, 9.2) Random split; two thirds of the original cohort	n= 1816 Age: 64 (51-74) Creatinine: 7.2 (5.5, 9.1) Random split; one third of the original cohort	c-statistic*: IC: 0.75(0.73-0.77) VC 0.73 (0.7-0.76) Both with good calibration.
Kan et al, 2013 (125)	The New Comorbidity Index (nCI) (11 comorbidities conditions included; age not part of the index; initially validated in separate dialysis populations without regard to age)	**Mortality** over the follow-up period (mean 3.25 years, median 1.56 years) in a population-based validation study cohort of elderly dialysis patients based on the presence of 11 comorbidities **at baseline at the start** of dialysis	[Inception cohort, in a **different study**, (126) included 4 incident cohorts (n=120134) and one prevalent cohort (n=142157); of all ages; drawn from USRDS data 1999-2000]	n= 21,043; Age: all > 65; stratified into groups by age eGFR: n.a 52% of patients in the lowest comorbidity score group Older age groups: more men, more comorbidities	c-statistic*: IC: [In the separate inception study: study: 0.669] (126) VC: 0.908 (0.897-0.919)
Dusseux et al, 2015 (127)	Predictive model (14 variables - including age, gender, body mass index, comorbidities, mobility, and temporary catheter at start)	Prediction of 3-year **survival** rate around 70% in people over 70 starting dialysis; based on French REIN registry data **at the time of initiation** (high survival rates could suggest eligibility for transplantation)	n=8955; Median Age: 78 (74-82); eGFR: n.a. (2002-2006)	n=7382; Median age: 79 (75-83) eGFR: n.a. initiating dialysis between (2007-2008)	c-statistic*: IC: 0.71 (0.69-0.71); VC: 0.71 (0.70-0.72); (Well calibrated)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
Thamer et al, 2015 (128)	Two predictive models - a simple risk score with 7 variables and a comprehensive risk score with 14 variables (age, gender, period of nephrology care, albumin, functional status, nursing home residents, comorbidities, hospitalisations)	Prediction of 3- and 6-month **mortality** after **initiation of dialysis** in people ≥ 67 based on data from USRDS and Medicare/Medicaid services who started dialysis in 2009-2010.	n= 52,796; Age: 76.9±6.5 eGFR: 12.2±5.1 (Jan 2009-June 2010)	n= 16,645; Age: 76.8±6.5 eGFR: 12.2±5.1 (July-Dec 2010)	c-statistic*: IC: 0.681 VC: 0.712 (Well calibrated)
Ivory et al, 2017 (129)	Ivory points score tool (8 variables, including: Age, weight, comorbidities, Late referral, etiology of CKD)	6-month **mortality** in a registry sample of adult patients **commencing dialysis** between 2000-2009 in Australia/New Zealand based on logistic regression analysis of factors available at dialysis initiation	n= 23,658 Age: 60± 15 in survivors; 69±13 in deaths eGFR: <15 in 95%	VC 1: temporal validation n= 5284 Age, eGFR - n.a All patients > 15 in the ANZDATA registry commencing dialysis in 2009-2011 VC 2: external validation n= 32,664 Age, eGFR - n.a All patients > 18 in the UK regional registry commencing dialysis in 1999-2007	c-statistic* IC: 0.751 (poor calibration) VC 1: 0.755 (acceptable calibration) VC 2: 0.713 (poor calibration)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
Chen et al, 2017 (130)	Predictive model (9 variables, including: Age, gender, race, primary disease, BMI, employment status, previous renal care, dialysis access, comorbidities)	5-year **mortality** in patients; baseline data **at the initiation of** dialysis in those ≥ 70 starting dialysis between 2006 and 2009 in the USRDS renal registry; to guide referral to kidney transplantation	n= 79,681 Age: ≥70 eGFR: n.a. Randomly selected cohort from among patients≥ 70 starting dialysis between 2006-2009 from USRDS registry data. 41 % had no nephrology care before initiating dialysis	VC 1 n= 79,681 Age: ≥70 eGFR: n.a. Randomly selected cohort from among patients≥ 70 starting dialysis between 2006-2009 from USRDS registry data 41 % had no nephrology care before initiating dialysis VC 2: n= 2397 Age: ≥ 70 eGFR: n.a. Patients ≥ 70 between 2006-2009, who received a kidney transplant before 2014	c-statistic* IC: 0.71 (0.70-0.71) VC 1: 0.71 VC 2: 0.60 (0.57-0.63: poor discrimination)
Data from incident patients on haemodialysis (HD)					
Mauri et al, 2008 (131)	Predictive model (10 variables – including age, gender, primary	1-year **mortality** in all patients starting HD; using registry data **at the time** of initiation	N= 3455 validation cohort was randomly chosen 60%	N= 2283 cohort developed from randomly	c-statistic*: IC: 0.78 VC: 0.78 (Well calibrated).

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
	renal disease, functional status, comorbidities, and malnutrition)		of the registry population. Age: 64.6±14.4 (overall) eGFR: n.a.	chosen 40% of same registry population (separate characteristics not provided)	
Floege et al, 2015 (132)	Predictive model (14 variables including: Age, smoking, BMI, comorbidities, Dialysis parameters, lab data)	1- and 2-year **mortality**, of all **incident** patients from a European patient database (AROii) between 2007 and 2009; validated in a population of **incident and prevalent** patients	1st inception cohort: n= 9722 Age: 64.4± 14.7 Creatinine: 565.4± 187.6 incident patients at < 3 months 2nd cohort: n= 8783 Age: 64.3±14.7 Creatinine: 614.1±201.7 incident patients 3-6 months	n= 10,615 age: 63.4±14.3 Creatinine: 777.9±256.4 Baseline data obtained at < 3 months of initiation in the DOPPS III cohort	c-statistic*: IC: n.a VC: 1-year: 0.72-0.73; 2-year: 0.72 R^2 value: IC: 1-year: 0.94; 2-year: 0.98 VC: n.a.
Fukuma et al, 2017 (133)	Predictive model. (6 variables included: Age, gender, dementia, mental health, moderate activity and ascending stairs)	1-year **decline in physical function** in dialysis patients ≥ 65, defined as a decline to a score of 0 on the 12 item Short Form Health Survey Physical Function Score from the **baseline score at initiation of HD.**	n= 593 Age: 71.6 ± 5.1 Dialysis vintage: 5.8±5.3 years Patients ≥65 included in the DOPPS Phases 1 and 2 in Japan, during 1996-2004 Mean BMI 20.5±2.7 Mean baseline	n= 447 Age: 71.9± 5.6 Dialysis vintage: 6.3±6.2 years Patients ≥65 included in the DOPPS Phases 3 and 4 in Japan, during 2005-2012 Mean BMI 21.0±2.5 Mean physical function score	c-statistic* IC: 0.79 (0.74-0.84) VC: 0.76 (0.72-0.8) (Well calibrated)

Author& Year	Index	Description	Inception Cohort (IC)	Validation Cohort (VC)	Accuracy / Results**
			physical function score: 59.4±25.8	a baseline: 62.8±25.8	

We identified 12 studies that compared dialysis treatments to conservative management without dialysis. Table 2-4 lists these studies, in chronological order, where the elderly have been the focus of comparisons between dialysis or conservative management.

Table 2-4: Studies Comparing conservative management (CM) and renal replacement therapy (RRT, all forms of dialysis)

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
Joly et al, 2003 (134)	Comparison of survival between CM and RRT in octogenarians; predictors of poor prognosis; most data obtained prospectively	All patients ≥ 80 with a creatinine clearance <10 ML/min (Cockcroft-Gault formula), not yet on dialysis; seen in a single French unit in 1989-2000 n= 146 (CM: 37; RRT: 107) Age: CM: 84.1±2.9; RRT: 83.2±2.9 Later referral, poor functional status and diabetes were more common in CM cohort; number of comorbidities similar between both cohorts	Survival: less with CM (8.9 vs 28.9 months) Factors significantly associated with: 1-year mortality: poor nutritional status, late referral and functional dependence Mortality beyond the first year: peripheral vascular disease	In those > 80, best 1-year survival is seen in those with early referral, normal BMI and good functional status (Most dialysis decisions here were taken by multidisciplinary team; all subsequently accepted by patients)
Smith et al, 2003 (67)	Comparison of survival between CM and RRT, in a group of pre-	All pre-dialysis patients presenting for assessment/counsellin g regarding RRT	Survival: Recommended CM: 6.3 vs 8.3	In those older, more functionally impaired, more comorbidities and

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
	dialysis patients in a single UK hospital, analysing outcomes according to initial choice and eventual treatment, prospective study	options in a renal clinic, classified into two groups based on recommended therapy-CM or RRT; followed for 3 to 57 months; eventual treatment choice and outcomes studied n= 321 (recommended: CM – 63; RRT – 258) Age: 61.5±15.4 (recommended: CM – 71±12; RRT – 59±15) RRT: 186 started treatment; rest died or chose CM CM: 11 switched to RRT eGFR: by derivation, < 10 in both groups	months if switched to RRT (not statistically significant) Cox PH: no survival benefit of RRT in those recommended for CM, regardless of eventual choice Likelihood of CM recommendation: Older, sicker, diabetic, more functionally impaired, less likely to survive one year	diabetes, who are recommended for CM, no survival benefit from RRT
Murtagh et al, 2007 (74)	Comparison of survival between CM and RRT in patients ≥ 75 from 4 UK renal units; retrospective study	All patients ≥ 75 receiving renal care, with survival calculated from the date of first recorded eGFR ≤15 n= 129 (CM 77, RRT 52). Median age: CM 83; RRT 79.6 Comorbidities: similar CM cohort: older; but otherwise similar	After eGFR ≤ 15: Median survival time: less in CM (540 Vs. 588 days) 1-year survival rate: lower in CM (68% vs 84%) 2-year survival rate: lower in CM (47% vs 76%) Survival in those with high comorbidity: no statistical difference CM vs RRT	In those > 75 with severe comorbidity, no significant survival advantage for RRT over CM
Carson et al, 2009 (135)	Comparison of clinical outcomes (survival, hospitalisation) for patients who had	Patients older than 70 who either started RRT or attended CM clinic from 1997 to 2003	CM cohort was older. Survival: less with CM [13.9 vs. 37.8 months]	In those > 70, RRT provided longer survival (by 2 years) than CM, but there were similar number of

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
	ESKD and chose either CM or RRT	n= 202 (CM: 29; RRT: 173) Age: CM: 81.6; RRT: 76.4 eGFR: Median value at start of RRT was 10.8. For CM group, survival calculated from the time they were estimated to reach eGFR 10.8. Comorbidity scores: similar in both groups	Hospitalisation: <u>less</u> with CM during follow up; CM cohort more likely to die at home or hospice than hospital (odds ratio 4.15)	hospital-free days in both RRT and CM
Chandna et al, 2011 (136)	Comparison of survival between CM and RRT in ESKD patients with high vs. low comorbidity in UK clinic from 1990-2008	All adults progressing to stage 5 CKD seen in clinic over 18 years; followed from the time of first recorded eGFR @10 to 15. n= 844 (CM 155, RRT 689) Ages: CM 77.5±7.6; RRT 58.5±15. eGFR: 13.2±1.4 in both groups at study entry. Comorbidity scales scored for every participant	CM was older and had greater comorbidities Survival (median) with low comorbidity: less in CM (29.4 Vs.36.8 months) Survival, severe comorbidity: less in CM (20.4 Vs.25.8 months) (non-significant difference in survival with severe comorbidity)	In those > 75 with severe comorbidity, no significant survival advantage for RRT over CM
Hussain et al, 2013 (16)	Comparison of survival, hospital admissions and palliative care access between CM and RRT cohorts of elderly patients in a single UK unit; studied retrospectively	All patients aged >70 and eGFR <20, receiving advice regarding CM vs RRT during pre-dialysis education. Survival was calculated from three time points: when the eGFR was <20, <15 and <12.	Survival from all three time points: less with CM Survival from eGFR <20 2.4 years less with CM. Difference in survival between	In those >80, no survival advantage for RRT over CM In those > 70, increasing performance score or increasing comorbidities

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
		n= 441 (CM 172, RRT 269). Age: CM 82±5.6; RRT 77±5 Comorbidity (CCI), WHO performance score worse in CM cohort; CM cohort more likely to be institutionalised	CM & RRT is reduced in: - those > 80: - when CCI score worsens - when performance score is low Hospitalisation risk: more with RRT than CM (RR 1.6) Palliative care review: more with CM (85% vs 4% of patients)	reduces the survival advantage for RRT over CM
Seow et al, 2013 (137)	Comparison of change in health-related quality of life between CM and RRT in patients with advanced age and severe comorbidity	Pre-dialysis patients eGFR 8 - 12, who were >75 or had CCI>8, seen in single Singapore hospital. Quality of life for assessed with KDQOL-SF v1.2, Chinese and English versions, administered by interviewer n=101 (CM 63, RRT 38) Age: CM: 78; RRT 71. eGFR: similar in both groups. eGFR decline: faster in RRT group	PCS, MCS stable in CM group; no significant difference from RRT group. RRT group: improved cognition function scale, but worse scores on effective kidney disease and burden of kidney disease scale	In those > 75 with severe comorbidity, RRT did not improve kidney-specific symptoms or significantly improve QOL domains compared to CM
Shum et al, 2014 (138)	Comparison of clinical outcomes (survival, hospitalisation, institutionalisation , EOL care) for Chinese patients with CKD stage 5	Adults ≥ 65; followed for at least 1.5 years from first dialysis assessment visit; retrospectively chosen from the period 2003-2010;	CM cohort was older, less likely to have home help with PD. Survival: less with CM [2.35 vs 3.75 years]	In those > 65, home-based PD provided greater survival than CM, with less hospitalisation and equal risk of

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
	that chose either CM or PD	n=199 (CM 42; PD 157) Age: CM 75.3±5.7; PD: 73.4±5.3 eGFR ≤15 for study inclusion	Hospitalisation: more with CM cohort than PD cohort even after adjusting for age, comorbidity and functional status Institutionalisation : risks were similar. EOL care: CM cohort more likely to receive renal palliative care; less bothersome interventions at EOL	institutionalisation
Brown et al, 2015 (139)	Comparison of survival, symptom burden and quality of life between CM and RRT in elderly patients in a single Australian unit; studied prospectively	All patients receiving care in pre-dialysis, renal supportive care or emergency dialysis start pathways. Symptoms, quality of life assessed using surveys. n= 467 (CM 122, RRT 345). Age: CM 82±9; RRT 67±14 eGFR at study entry: 16 in both groups	Survival: less with CM (20 vs 33 months) Survival in those > 75: less with CM (19 vs 31 months) Mean survival from eGFR<15: less with CM (13 vs 20 months) Mean survival, eGFR<15, age> 75: less with CM (aHR 4.4) mean survival, age>75, comorbidities (IHD or CHF) ≥ 2: not statistically different Symptom control: similar in both CM and RRT Quality of life changes:	In those >75, with cardiac plus other comorbidities, no survival advantages from RRT over CM

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
			similar in both CM and RRT	
Verberne et al, 2016 (140)	Comparison of survival between CM and RRT in patients ≥ 70; retrospective study single Dutch hospital	All patients ≥ 70 receiving renal care in one centre, eGFR <20. Survival calculated from time of decision regarding RRT/CM n= 311 (CM 107, RRT 204). Age: CM 82.5±4.5; RRT 75.9±4.4 eGFR: CM 15.3, RRT 13.1 eGFR decline: similar in both groups Comorbidities: similar	Survival: less with CM (0.5 vs 2.8 years at eGFR<10; 1.5 vs 3.1 years at eGFR<15) Survival in those over 80: no statistically significant advantage (1.4 Vs 2.1 years, p 0.08) Survival in those with high comorbidity: benefit of RRT significantly reduced (1 vs 1.8 years, CM vs RRT)	In those > 80, no significant survival advantages for RRT over CM
Martinez Echevers et al, 2016 (141)	Comparison of survival between CM and RRT in elderly patients in a single Spanish unit; studied prospectively	All patients aged >70 receiving care in the advanced CKD clinic, with separate analyses in those with CKD stage 5 regarding CM vs RRT and survival Group with eGFR<15: n= 162 (CM 93, RRT 69). Median Age: CM 78; RRT 76 eGFR at study entry: 14 in both groups	Survival (overall study duration): less with CM (39 vs 65 months) Survival from eGFR<15: less with CM (21 vs 46 months) Survival in those > 75: less with CM (p=0.003) Survival in those > 80: no difference between CM vs RRT Survival in those with IHD - no difference between CM vs RRT Survival with high comorbidity CCI score: less with CM (p=0.009)	In those >80, no survival advantages from RRT over CM In those > 70 with IHD, survival benefit of RRT is reduced

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
Chandna et al. 2016 (142)	Investigation of role of rate of kidney function decline on survival and treatment choices in older ESKD patients seen in UK clinic from 1995-2010	Patients over 75 years old progressing to eGFR 10-15, seen in renal clinics between 1995-2010; (second follow-up eGFR taken prior to dialysis start or prior to death (CM patients) to calculate the rate of decline of eGFR) n= 250 (CM: 158; RRT: 92) Age: 80.9±4 (CM: 82±4.1; RRT: 79.1±3.1) Index eGFR: 13.3±1.4 in both groups. Follow-up eGFR: CM: 8.8±3.2; RRT: 6±2.5 Median rates of eGFR decline (ml/min/mth): CM: 0.21; RRT - 0.45; (p<0.001)	CM cohort: similar age, more comorbidities, but slower rate of decline in eGFR Survival: less in CM (23.1 vs 38.2 months) Survival with high comorbidity: less in CM (20.3 vs 28.4 months; p<0.049) High rate of eGFR decline: worse survival in CM, minimal effect in RRT Predictors of RRT choice: Age > 75, gender, comorbidity, rate of decline of eGFR.	In those > 75 with high comorbidity, only marginal advantage of RRT Rapid rates of eGFR decline worsens survival in those > 75 managed with CM CM choice is more often taken in patients with low rates of decline
Reindl-Schwaighofer et al, 2017 (143)	Comparison of survival between CM and RRT in the same era, using Austrian registry data for haemodialysis patients; studied retrospectively	All patients > 65 years starting haemodialysis between 2002 and 2009 in the Austrian dialysis and transplant registry were compared to patients managed conservatively, after the GFR declined <10; in a single hospital (aged >65, in 2002 – 2009); bootstrapping used for propensity scores	CM cohort: 95% female, more comorbidities Survival: less with CM (1.1 months vs 26.9 months) Survival benefit: less with CM (HD hazard ratio for death 0.39) survival benefit beyond two months: better with CM (non-significant)	In those >65, with comorbidities, survival benefit for RRT did not persist beyond 2.9 months (females) or 1.9 months (males) compared to CM

Author/ year	Aim/objectives	Population of interest	Main findings*	Conclusions / Comments
		n = CM – 174; RRT (only HD) – 8622 Age: CM 81.22±7.23; RRT 74.06±5.78 eGFR: CM <10; RRT - not specified		

*Confidence intervals, interquartile ranges and P values not included for all articles.

Characteristics of studies describing effects on quality of life

Eighty studies were selected as being representative of research that evaluated the factors that influence the quality of life in older adults on dialysis. Of these, 29 were clinical research papers, the rest being reviews of related topics or expert opinion. Among the 29 articles reporting on original clinical research, 24 used questionnaires or surveys to interrogate quality of life. The supplementary materials include a list of the commonly used instruments to measure quality of life in the elders on dialysis.

Content and scope of articles discussing factors influencing quality of life

Table 2-5 lists the factors affecting quality of life, identified from analyses of the included articles. They have been separated into modifiable and non-modifiable factors for convenience.

Table 2-5: Factors affecting quality of life

Potentially modifiable factors (pre-dialysis)	Non-modifiable factors (pre-dialysis)
Physical status	Age
Functional decline	Gender
Frailty	Race
Symptom burden	Socio-economic status (some aspects amenable to interventions)
Unplanned dialysis starts	Comorbidities (some aspects amenable to interventions)
Depression	Dialysis -related factors (dialysis vintage, session length, regimens, etc.)
Cognitive impairment	
Positive social relationships	
Sleep disturbances	
Impaired nutrition	
Cardiovascular health	

Age had an impact on quality of life. While physical aspects of quality of life in the elders was low, especially once on dialysis, other aspects of quality of life such as life satisfaction, mental component scores or social well-being appeared to be more stable in older than younger patients (144,145).

Researchers who compared the quality of life outcomes in older people between the conservatively managed pathway versus the renal replacement pathway reported either no major differences between the two, or worse quality of life with dialysis (52,139,146).

Psychological factors were relevant to quality of life. Depression scores, spiritual and emotional well-being and even cognitive impairment have been reported to affect quality of life (147,148). Functional impairments and frailty, diminished exercise and impaired activities of daily living all worsened quality of life. Despite diminishing functional status, rates of hospitalisation were not significantly different between older and younger patients on dialysis (149). For patients already on dialysis, several dialysis -related factors contributed to quality of life. These included dialysis vintage, alterations

in dialysis regimes or the duration of dialysis sessions. Finally, other comorbidities such as diabetes, myocardial infarction and stroke worsened quality of life.

Characteristics of studies describing lived experience with advanced renal disease

Ninety-four studies that reported on the experiences of older adults living with advanced renal failure were included. The majority of articles (74 of 94) detailed original clinical research; 23 employed qualitative analysis, usually in the form of interview or focus group analysis, while 29 used a particular tool or instrument to assess one of the aspects of experience. A list of the common instruments used in these studies is provided in the appendix, sorted according to the area of analysis.

Content and scope of studies describing lived experience with advanced renal disease.

Several studies used scores or indices to study life on dialysis; importance is also given to symptoms, functional and cognitive aspects (and, particularly in this age group, to falls). Discussions of decision-making, survival and ageing were also common.

Elderly patients reported difficulties in getting information, feeling disempowered and dominated by the healthcare team and not being part of decisions (150). Patients reporting disempowerment were more likely to regret the decision to go onto dialysis; this was more common if they started dialysis from family compulsions (151). Patients wanted greater involvement in deciding practical aspects of dialysis such as dry weight, the time of treatment, dietary restrictions or the access to use for dialysis (152).

Coping and adaptation to treatment were important parts of the narrative. Successful coping was vital (153). Patients that coped successfully had "a transformed care

dynamic, positive appraisal and active everyday engagement" (153). Useful coping strategies included letting go, overcoming, keeping a sense of humour, looking at the good side of things and thinking positively (154,155).

The incurability of renal failure forces patients to reinvent themselves, make compromises or adopt beliefs or behaviours discordant with medical opinion (156–159). Despite these burdens, the majority of patients reported satisfaction with treatment and improvement of symptoms; another study found that the majority of patients reported no decision regret or ambivalence about starting dialysis (46,160). It should be noted, however, that patients' decisions, goals and expectations are not static but change with time as different issues emerge (151,161).

Patients constantly reflect on themselves in relation to others - being a burden, receiving help or having other relationships (157,162). Partnership was frequently mentioned, whether spousal or with professionals (153,163). Patients reported close and supportive relationships with healthcare professionals in some centres; dialysis nurses often encouraged patients to be independent and assisted with coping (160). Otherwise, elders reflected on the busy cultures of units, with infrequent opportunities to speak to doctors (164).

Several included studies referred to the effects of dialysis on the functional status of older patients, particularly in the first six months where up to 30% face decline (56,165,166). This is even worse for patients living in nursing homes where 61% declined in functional status or died within the first three months; this figure was 87% at one year (58). Falls are common, particularly soon after dialysis (167).

The symptom burden was high, and this was confirmed by qualitative studies which provided stories of suffering and burden inflicted by dialysis (168). Despite this, scores of mental components of quality of life and satisfaction with life appear to be stable and

equal to or better than that for younger patients (144). Other correlates of a good quality of life in these studies included living with family rather than alone or in a nursing home and having widespread social relationships. The social well-being of elderly dialysis patients did not decline significantly with time (169,170). Physical scores were uniformly lower (58,171,172). There were several interactions among these factors, such as those between cognition and depression, physical decline and risk of falling and insomnia and depression (173,174). Octogenarians were frequently hospitalised for infections; while those patients who had access to a conservative management pathway were less likely to be admitted to hospital, particularly at the end of life (16,149).

Older patients are aware of impending mortality and frequently contemplate death (175). These topics are difficult to talk about (176). The haemodialysis machine is seen as a lifeline as it attempts to relieve suffering even though dialysis can be seen as a prison, or between life and death (150,156,162). Thoughts of stopping dialysis arise often - increasing age, female gender, dementia and prior cerebral vascular disease are risk factors for withdrawal (177,178).

Characteristics of studies reporting on information needs of the elderly

A total of 32 articles, mostly published in the last 10 years, were concerned with information needs of elderly patients with advanced renal failure. Seventeen articles were original research papers, eight were opinion pieces and six were reviews (predominantly narrative reviews). Most research was in the qualitative realm (12/17 interviews and focus groups analysis; 4/17 survey-based analysis).

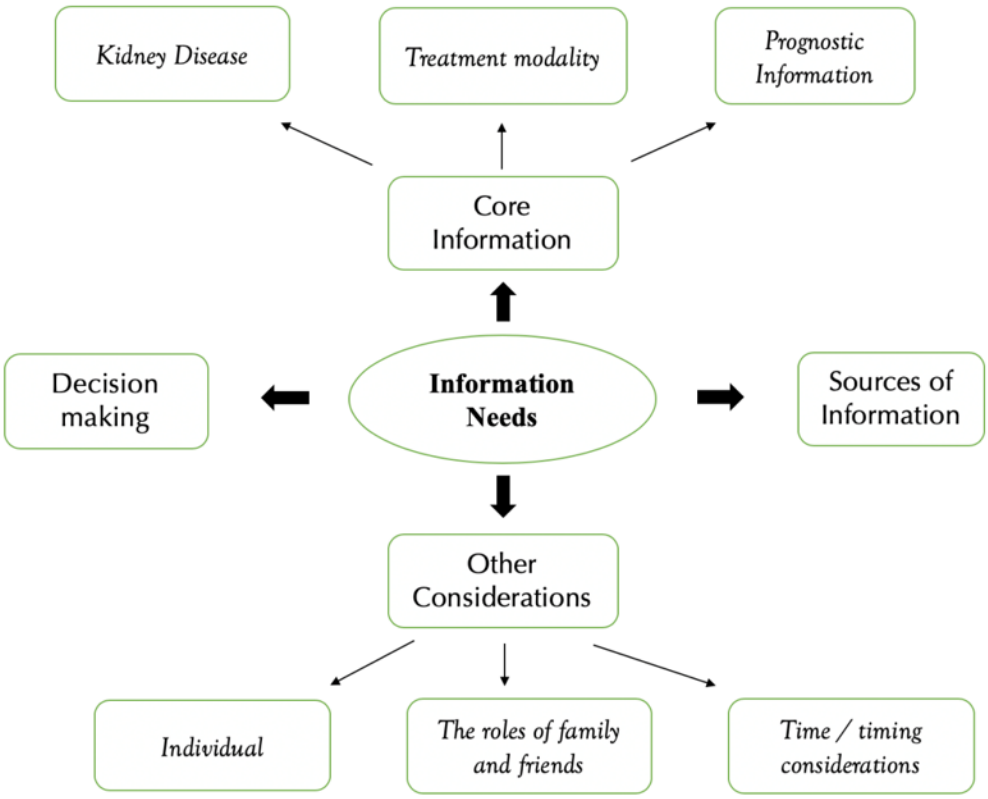

Figure 2-4 Information needs - themes elicited

Content and scope of studies reporting on information needs in the elderly

Articles discussed broad themes which are summarised in Figure 2-4 above. The most frequently recurring theme related to the need for complete information about treatment modalities, including non-dialysis pathways. Such information is not uniformly provided to patients - discussion about conservative care options, for instance, was more likely to happen if the particular renal unit had an established conservative treatment pathway (68).

Considering the perceived uncertainty regarding kidney disease and its treatment requirements, patients desire information about kidney disease, progression and the symptoms that may arise, especially with non-dialysis pathways of treatment. Even

though survival was an important aspect of prognosis relevance to patients, they often report not receiving information regarding this. Clinicians are hesitant or unwilling to discuss prognosis for many reasons (because of uncertainty, not wanting to take away hope, et cetera) (20). Yet, this is vital information which could affect the choices they make about therapy. Fine and colleagues, in two separate questionnaire-based studies on pre-dialysis populations, showed that patients expect doctors to give them prognostic information even without being prompted (101,102).

Mortality, and thoughts about dying, were very common, especially in those considering conservative treatment or discontinuation of dialysis. Some patients were reticent to engage with the topic of discontinuation and death because they found themselves overwhelmed, and continued dialysis even without making a deliberate choice to do so - they did not want to think about other options since they knew that death was certain without dialysis (37). The frequent discussion of mortality and consideration of future care by elderly patients suggests that they will be amenable to advance care planning discussions.

Information needs and dialysis decisions are a fluid process, subject to change for most patients (179). With limited choices, the alternative to dialysis is often interpreted as death (40). Patients welcomed the opportunity to participate in shared decision-making but regretted the "pressure" they felt from the clinical team for a decision (180). They sought information on the outcomes if they did not have dialysis or withdrew from treatment (37). In general, they requested information pertinent to the elderly and reflective of patient-centred values and considerations (73). Patients had their own estimates about the importance of quality of life for survival rather than the perceived benefits of treatment (42,73,181). As expected, patients had different preferred learning styles - for instance, some preferred visual aids or written information rather than

verbal. It was important that information be presented in small chunks, in simple rather than complex terms and without medical jargon (182).

Several practical issues were important to patients. These included information on the need for lifestyle, diet or fluid intake changes, travel, hospital visits, anticipated support needs and availability of support services in the community (8).

2.2.5 Discussion

The aim of the scoping review was to collate the information available for decision-making in older adults considering dialysis, so as to serve as a reference for physicians and others involved in shared decision-making. While several prognostic models and prediction instruments that estimate survival have been developed, decision-making for patients, carers and their healthcare professionals does not rely merely on survival statistics (183). Rather, a deliberate approach, which takes into consideration several other factors, including the needs of the patients themselves, should be considered. We gathered information on prognosis, the factors affecting quality of life, the lived experiences of older patients with advanced renal failure and the information needs of these patients.

Addressing prognosis, the majority of studies focused on mortality as an outcome. Several variables have been reported as important prognostic factors among the included articles, with advancing age and increasing comorbidity exerting prominent influence. We also identified a variety of prognostic indices available for use in the older population; we anticipate that this will benefit clinicians who can choose tools relevant to their own patients. Use of these indices have been recommended as an important part of the shared decision-making process (71,72). We specifically recommend the tools and models developed in populations with older individuals,

since advancing age has its own prognostic import which needs to be considered separate from many of the other factors that operate in people of all ages (103). It is worthwhile remembering that the information obtained using prognostic indices can be used not only to inform patients of risk, but also to help plan treatment pathways. Given the lower risk of progression of renal disease in the elderly, a prognostic index predicting risk of progression to ESKD will be useful to identify a group of patients most likely to progress and therefore most in need of planning for therapy. The Kidney Failure Risk Equation developed by Tangri et al in a Canadian population (ages around 70 in original and validation cohorts) has now been validated multi-nationally (mean age 74 in 31 cohorts in the Chronic Kidney Disease Prognosis Consortium) (84,184). Available in 4- and 8-variable formats, the equation is now part of popular handheld applications, and can be recommended for routine use – the development of baseline risk adjustments for non- north American populations increases its accuracy. For assessment of mortality risk, the Bansal index, which was derived in an elderly population, is useful because it predicts the risk of death before reaching ESKD (118). Potentially, this index can be used to select a group of elderly individuals at high risk for progression. However, it must be noted that the population used for the development of the Bansal score had a lower number of patients with CKD stages 4 and 5; also, the score does not take into consideration other important mortality risks such as frailty that are predictive in this population (185,186). Currently, the Bansal score can be used to identify patients at high risk for mortality that are more suited to a conservative line of management.

Several papers reported that there is a cohort of very elderly patients, above 80 years of age, with multiple comorbidities, who derive little survival benefit from being on dialysis (16,140,141). The data in table 2.4 summarises the differences in survival between conservative and dialysis management. Although particular modalities of

dialysis are not compared with each other, some generalisations can be made. First, most studies are single-centre efforts, and similar standards of conservative management may not be replicable across different centres. Additionally, differing definitions of comorbidity may have been used. Nevertheless, it appears that there is no survival advantage to rail replacement therapy in those aged over 80. For those aged over 75, the presence of comorbidities takes away any survival advantage of renal replacement therapy. In those 65 or 70 years of age and above, in general, renal replacement therapy has greater survival than conservative management except, once more, in the presence of severe comorbidities, where the difference is less significant.

When elders discuss treatments such as dialysis, there is often a consideration of quality of life, which is often rated as important as 'quantity', or longevity. There is a paucity of original research on the quality of life and the (potentially modifiable) factors that affect quality of life, as also evidenced by a 2017 systematic review (48). Included studies (29 detailing clinical research) suggests that age, gender, physical status, comorbidities, cognition and psychological variables such as depression affected quality-of-life outcomes in the elderly (63,183,187,188). There are apparently no significant differences in quality of life between dialysis and conservative management (17,52,137,139). Our review identified a few potentially modifiable factors that could improve quality of life in elders considering dialysis. As shown in Table 4, some of these factors, such as depression, sleep disturbances or poor nutrition may be amenable to intervention in the pre-dialysis stage itself. Brown (2012) suggests that engaging patients in discussion, emphasizing lifestyle effects of treatment, considering benefits of all interventions - even renal clinic visits - are additional measures to improve quality of life in elders with advanced CKD (183).

Multiple social connections and close family relationships appear to improve the experience of dialysis. While some patients were able to cope successfully and "reinvent themselves" in their new lives, others described negative outcomes (58). The lived experience of these patients is dominated by disempowerment, lack of knowledge, cognitive impairment, depression, difficulties with strict regulations regarding diet, fluid and dialysis timings, and finally, functional decline, which called into question their relationships with family and made them feel a burden to others. These reports suggest that clinicians should measure physical status, functional impairment and cognitive status frequently so that appropriate interventions can be planned early (189). There are dominant thoughts regarding death in this population, suggesting the role for discussions regarding end-of-life care or advance care directives. Healthcare professionals play important roles in these patients' lives.

Finally, we surveyed the literature on patients' information needs. It is evident that there are several areas where information provision to patients could be improved. Patients are interested in their prognosis (survival, quality of life, eventual outcome) with and without dialysis treatment (73). Older patients already on dialysis tell us that they would have liked more practical knowledge about what is actually involved in having dialysis, as well as the effect of dialysis daily life. Matters relevant to the elderly, presented in a non-technical, jargon-free manner, involving patients, and giving them "more rather than less" information can be recommended. Frequent thoughts about death and dying in this age group mandate that healthcare professionals attempts to engage their patients with these topics and discuss matters such as advance care planning. Table 2-6 summarises these concepts and provides ideas for future research.

Table 2-6: Information for shared decision-making and areas for research

Domains to consider	Areas for future research
Survival (use prognostic indices developed in the older population).	Indices that predict outcomes other than survival (e.g., quality of life, functional decline)
Quality of life outcomes (explore patients' expectations)	Factors that affect quality of life in elders; modifying these factors; impact on outcomes
Lessons from the **experience of older people** on treatment (lifestyle changes; functional and cognitive worsening; impact on daily life, relationships; symptom burden).	Modifiable factors that might improve the experience of treatment (dialysis or conservative management)
Involve family/friends (acknowledging their multiple, important roles, especially in frail, dependent elders).	Provision of information, support and follow-up of carers of older adults with advanced CKD
Tailor information to the older person (avoid medical jargon, purposively include prognosis information, consider cognitive impairment and depression).	Improving communication of information; and monitoring delivery and understanding

Strengths and limitations

In our estimation, this is the first scoping review focused specifically on the older patient and the wide spectrum of knowledge relevant to the shared decision-making process for ESRD. We include a comprehensive survey of prognostic instruments developed in this population, as well as a summary of comparisons between conservative management and dialysis, both of which will be useful resources for clinicians.

Studies were not graded on the basis of quality, since this was a scoping review. The preponderance of included work from Western, English-speaking nations ignores

information from other parts of the world. Research done on non-professional carers has not been included because of the difficulty in specifically identifying research done on carers of older adults with advanced renal failure. We did not compare between dialysis modalities or transplantation – often, there are regional or local factors that dictate availability of these choices for older adults. However, despite these limitations, we believe our review not only summarises a diverse body of knowledge and identifies potential gaps, but also presents this information with practical interpretations that are likely to be useful for clinicians.

2.2.6 Conclusion

Length of survival is an important consideration when older patients compare dialysis treatment to conservative care. Physicians now have several validated indices to help with prognostication. However, as evident from this scoping review, longevity or survival are not the only factors patients and families take into account. Therefore, discussions about outcome ought to also address other expectations of treatment, such as the anticipated quality of life or functional status. All information ought to be presented in a manner that the older patient can easily understand, retain and apply. When providing advice, a well-rounded, holistic approach that is informed by the experiences and expectations of older adults is likely to lead to optimal decisions and better patient-centred outcomes.

Chapter 3 :
Symptom burden, recognition and effects on quality of life

3.1 Patient-reported symptoms and quality of life

As described previously, in addition to poor survival, the experience of dialysis is characterised by poor measures of self-reported quality of life, particularly in the physical domain. It is worthwhile considering here the factors that influence health-related quality of life (HRQOL) in general.

Quality of life is an abstract concept, which means different things to different people. On its website, in a Section on measurement of quality of life, the World Health Organisation (WHO) defines quality of life as follows (190):

> *" …quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."*

Health-related quality of life is therefore one part of the overall spectrum of quality of life. Several models have been used to study the components of health-related quality of life (HRQOL), and in most models, the presence of symptoms directly affects the

HRQOL. For instance, in the Ferrans modification of the classic Wilson-Cleary model (30,191), symptoms, functional status and health perceptions interact on the biological substrate to contribute to overall HRQOL. Since the presence of several persistent symptoms is a characteristic feature of the experience of dialysis, it is possible that poorly treated symptoms contribute significantly to the low quality of life reported by dialysis patients. In fact, this relationship between symptoms and quality of life in patients with end-stage kidney disease has been extensively reported in the literature (91,139,192–198); we have also reported on this in our scoping review detailed in Chapter 2.

3.1.1 Symptom burden in dialysis: Prevalence and recognition by clinicians

Patients on dialysis have a significant symptom burden, reported to be similar to patients with terminal cancer (59). The excessive burden of symptoms in dialysis patients has been reported in research from all over the world – UK (199,200), Spain (201), Hong Kong (194), USA (202), Canada (203,204), Taiwan (205), Australia (91,139), and Sri Lanka (206).

Researchers have attempted to explore why a severe symptom burden persists in dialysis patients (207,208). There are practical difficulties in managing the symptoms of patients with ESKD, which are often recalcitrant. Renal physicians may not consider symptom management as their responsibility; similarly, patients may not report their symptoms to renal clinicians because of the belief that the symptoms are not related to their kidney disease. In addition to these difficulties with symptom management, attention has also focused on poor recognition of symptoms by providers. This could contribute to the problem of persistent symptoms, since in order to effectively treat

symptoms, proper symptom recognition is the first step. Linking these observations together, one could postulate that the low quality of life of patients on dialysis is affected by their persistent, severe symptoms, and that these symptoms persist also because of poor recognition by their clinicians. In fact, a paper from the United States by Weisbord and colleagues, published in 2007, suggested that clinicians do not recognise their patients' symptoms very well (209). In this article, they compared patient-reported symptoms to symptoms identified by healthcare providers (predominantly dialysis nurses and technicians) and showed very poor sensitivity toward patients' symptoms by the clinical team. This was an important finding, and we were eager to see if such a finding would be replicated in our population.

Compared to the population described by Weisbord and colleagues, the dialysis population in North and North-West Tasmania has subtle differences, and it was possible that clinician recognition of symptoms would be better (209). The dialysis populations are smaller, with a physician to dialysis patient ratio of approximately 1: 5, and a dialysis nurse to dialysis patient ratio of approximately 1: 4. Within the dialysis units, dialysis nurses are "allotted" particular patients, which means that each nurse is responsible for a few patients as "primary" patients (personal communications). All these factors suggested that there was greater contact between clinicians and patients in the local population and suggested that clinician recognition of patient symptoms could potentially be better than that reported in the literature.

3.1.2 Objectives of the research project

This research project was conceived to explore, in a local dialysis population, the relationships between symptoms, their recognition and quality of life. We designed a project that used survey-based descriptive research to document symptoms and quality

of life in the dialysis population. Our main research aim was to look for correlations between symptoms and quality of life, in order to understand whether severe symptoms were responsible for poor quality of life outcomes. Additional expected outcomes from the study were to document the recognition of symptoms by nurses and clinicians, and to compare this recognition with patient-reported symptoms so as to be able to gauge the degree of agreement with patient reports and the clinicians' sensitivity to symptoms. We were also interested in comparing symptoms and quality of life in the older population (age >70) to that in the younger population.

3.2 Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life

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Original Article

Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life

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SUMMARY AT A GLANCE

This preliminary observational study investigated the recognition of symptom burden in haemodialysis patients by healthcare staff. The results showed that nephrologists' tended to under recognize patient symptom burden, whereas nursing staff performed better in this task.

ABSTRACT:

Aim: **We investigated the symptom burden in adults on haemodialysis, the recognition of symptoms by nurses and nephrologists, and the relationship between symptoms and quality of life.**

Methods: **In this cross-sectional observational study, symptoms and quality of life in haemodialysis patients were determined using validated surveys. Nurses and nephrologists independently estimated their patients' symptoms, and these estimates were compared with patient responses (sensitivity; kappa values for interrater agreement). Associations between symptoms and quality of life were assessed using multi-level regression.**

Results: **Forty-three patients, 18 nurses and 3 nephrologists participated. The commonest symptoms (95%CI) reported by patients were weakness, 69% (53 to 82); poor mobility, 44% (29 to 60); and drowsiness, 44% (29 to 60). Sensitivity less than 50% was seen towards 11 of 17 symptoms in nurse ratings compared with 15 of 17 in nephrologist ratings. Agreement with patient symptom ratings was mostly 'fair' (0.21–0.4), with nurses' scores showing greater agreement than nephrologists'. Physical, mental and kidney disease component summary scores of quality of life were negatively associated with total symptom score and the number of 'major' symptoms (r^2 values 0.3–0.36); while with multivariate regression, 50% to 60% of the variance in these scores was accounted for by parsimonious models containing symptoms such as pain and poor mobility.**

Conclusion: **Symptom burden worsened quality of life scores in haemodialysis patients. Clinician recognition of symptom burden was inaccurate, although nurses were more accurate than nephrologists. Using patient-completed surveys or including dialysis nurse feedback in routine outpatient settings may help improve symptom recognition by nephrologists.**

Adults on maintenance dialysis experience a poor quality of life (QOL) compared with their peers,[1] similar to those experiencing other chronic illnesses such as cancer.[2,3] Several studies of dialysis patients in the last three decades have demonstrated poor QOL outcomes, suggesting that despite advancements in renal replacement therapy, QOL has been difficult to improve.[4–8]

Patients undergoing maintenance dialysis experience a significant symptom burden, and this can directly influence their perceived QOL.[6,9–12] Heath-related quality of life (HRQOL), part of the larger canvas of overall QOL, is a particular area of interest for clinicians. HRQOL is influenced by illness, treatment and its perceptions, and has been described as a composite of physical, psychological and social domains, each of which is composed of several contributing factors.[11] A comprehensive theoretical model detailing how various factors interact in affecting QOL was proposed by Ferrans and colleagues.[13,14] In this model, symptoms (physical, emotional and cognitive) have effects on QOL and are also influenced by other variables. Because several symptoms in dialysis patients are amenable to treatment, it can be postulated that reduction of the symptom burden could improve HRQOL. However, the identification and treatment of symptoms in dialysis patients are not straightforward. Suboptimal recognition of patients' symptoms by their healthcare providers has been described in the dialysis population.[15]

We studied symptoms, their recognition and their interaction with QOL in an Australian dialysis population using validated symptom and QOL questionnaires. The purpose of this study was threefold: firstly, to obtain a cross-sectional snapshot of the symptoms and QOL, secondly, to study the recognition of symptoms by healthcare providers (nurses and nephrologists) and finally, to document the interactions between symptoms, their recognition and QOL.

METHODS

Study participants

A cross-sectional survey of maintenance haemodialysis patients, dialysis nurses and nephrologists was conducted at the satellite dialysis facility of a regional hospital in Tasmania, Australia (Australian Standard Geographical Classification Remoteness Area – RA2, Inner Regional).[16] All adult (>18 years old) patients undergoing regular in-centre haemodialysis three times a week (for at least 3 months before enrolment) were eligible for inclusion. We excluded patients that had been hospitalized in the 1 month prior to data collection, because being in the hospital would mean greater interaction with the healthcare providers than the usual norm. Consecutive sampling was used, and all eligible patients were offered participation. Because this was an exploratory study within a small population (52 eligible patients in all), no sample size calculation was made. Participating healthcare providers consisted of each patient's designated 'primary dialysis nurse' and treating nephrologist.

Materials and procedures

The Palliative Outcome Score-Renal (POS-Renal) questionnaire, validated for use in patients with advanced kidney disease and recommended by recent guidelines, was used to survey symptoms.[17–20] The POS-Renal lists the same 17 symptoms (e.g. pain, shortness of breath and itching) on both patient-completed and staff-completed forms. Symptoms are rated on a 5-point Likert scale (see later). Healthcare providers independently rated the severity of each symptom in their patients, without seeing the results of patient – completed surveys.

Self-reported QOL scores were collected from patients using the Kidney Diseases Quality of Life-Short Form 1.3 (KDQOL-SF 1.3).[21] Responses to this 80-item questionnaire are used to calculate scores for multiple subscales of QOL, as well as three overall composite scores – the SF-12 Physical Composite (PCS), SF-12 Mental Composite (MCS) and the Kidney Disease Component Score (KDCS).

Data collection

The study protocol was approved by the Tasmanian Health and Medical Human Research Ethics Committee (H0013482). Data collection from consenting patients (and their dialysis nurses) occurred during the week prior to their scheduled outpatient visit to their nephrologist. Patients completed the POS-Renal and the KDQOL-SF 1.3 forms. Nephrologists completed the symptom surveys within 48 h of seeing the patient in the outpatient clinic. Data were collected from December 2013 to March 2014.

Demographic data collected from the dialysis and hospital records included age, gender, years on dialysis and the presence of comorbidities. Comorbidities and functional status were ascribed as per the treating nephrologist. The Charlson's Comorbidity Index[22,23] and the Karnofsky Functional Index[24] were calculated for each patient. Biochemical parameters reported within 1 month of the data collection week were collected – including haemoglobin, albumin, phosphate and dialysis Kt/V (measured with Diascan© real-time monitoring system, Gambro AB/Baxter International Inc., USA).

Data analysis

Symptom burden, sensitivity and interrater agreement

The total symptom score was used to reflect symptom burden. Symptom scores were converted into categorical variables for sensitivity analysis, with two categories possible; 'minor' or 'major'. Scores of 0 (not at all) and 1 (slightly, but not bothered to be rid of it) were categorized as 'minor', while scores of 2 (limits some activity or concentration), 3 (activities/concentration markedly affected) and 4 (unable to think of anything else) were categorized as 'major'. The number of symptoms reported as major was calculated.

We calculated the sensitivity of symptom recognition using the patients' reports as the gold standard, shown in Table 1 (as previously described by Weisbord *et al.*).[15] Sensitivity {(TP/[TP + FN]) × 100%} of recognition – which was the probability of identifying a symptom as 'major' when the patient also identifies it as being 'major' – was calculated for all the symptoms for both nurses and nephrologists.

A rating for a symptom by patient and by a healthcare provider was considered to be in agreement if both scored it either 'minor' or 'major'. We used the Cohen's kappa statistic to determine interrater 'agreement'. The kappa statistic is standardized so that a value of zero is 'exactly that expected by mere chance' while a value of 1 denotes 'perfect agreement'.[24]

Table 1 Symptom classification for estimating the sensitivity of recognition

Description	Patient scored as	Staff scored as
True positive (TP)	2, 3 or 4 [Major]	2, 3 or 4 [Major]
True negative (TN)	0 or 1 [Minor]	0 or 1 [Minor]
False positive (FP)	0 or 1 [Minor]	2, 3 or 4 [Major]
False negative (FN)	2, 3 or 4 [Major]	0 or 1 [Minor]

Quality of life

The KDQOL-SF 1.3 was scored using the Microsoft Excel-based KDQOL-SF 1.3 Scoring Program (v2.0).[26] This program generates scores for each patient for each of the subscales listed earlier, as well as descriptive statistics and summary scores across all patients.

Relationship between quality of life and symptom burden

Univariate regression was used to analyse relationships between total symptom score and the number of symptoms reported as 'major' with the summary scores of QOL – Kidney Disease Component Summary (KDCS), Physical Component Summary (PCS) and Mental Component Summary (MCS). We also constructed mixed-effects linear regression models for KDCS, PCS and MCS, using the five most common symptoms in our population. Observations that had missing data for a particular component were excluded from the related analysis. Data analysis was performed using Microsoft Excel and Stata v 12.1 (Stata Corp, College Station, TX, USA).

RESULTS

Of 52 patients invited, 43 (82.6%) consented to participate in the study (Table 2). All healthcare providers approached consented to participate, including 3 nephrologists and 18 haemodialysis nurses. The study population was predominantly Caucasian (Caucasian 41, Torres Straits Islander 1, Filipino 1).

Frequency of symptoms

The mean total symptom score per patient (possible range: 0 to 68) was 16.8 (SD = 11.3). On average, patients scored 5 symptoms out of 17 as 'major' (range: 1 to 9 symptoms). Among symptoms reported as major by patients, the most common were weakness or lack of energy (in 69%), followed by poor mobility, drowsiness, difficulty sleeping and shortness of breath (Table 3).

Table 2 Characteristics of the study population

Characteristic	Patient data ($n = 43$)
Mean age (SD)	63.9 (±15.7)
Male/female gender (%)	63/37
Mean years on dialysis (SD)	5.2 (±4.2)
Mean Charlson's comorbidity score (SD)	6.5 (±3.2)
Mean Karnofsky score (SD)	70 (±10)
Diabetes (%)	40
Hypertension (%)	91
Ischaemic heart disease (%)	42
Peripheral vascular disease (%)	33
Mean Biochemical parameters (SD)	
Haemoglobin g/L	113.3 (±13.5)
Albumin g/L	33 (±3.8)
Phosphate mmol/L	1.7 (±0.6)
Kt/V Urea	1.4 (±0.2)

Nurse/nephrologist sensitivity and interrater agreement

The mean (SD) total symptom score assigned by nurses to their patients was 14 (8.93), and the average (SD) number of symptoms that they recorded as 'major' for their patients was 4 (4). For nephrologists, the mean (SD) total score was only 5 (6) and the average (SD) number of symptoms per patient reported as 'major' was 1.5 (2).

Sensitivity was less than 50% for nurses in 11 out of 17 symptoms. Among nephrologists, sensitivity was less than 50% in 15 out of 17 symptoms (Table 3). The symptoms that were identified with the highest sensitivity scores were similar for both nurses and nephrologists – poor mobility (reported as major by 41% of patients), feeling depressed (seen in 15% of patients), weakness/lack of energy (seen in 66% of patients) and pain (seen in 27% of patients).

Table 3 lists the values of the kappa statistic of interrater agreement. Agreement between nurses and patients was 'fair' for 10 symptoms, 'moderate' for two and 'substantial' for one (poor mobility). For comparisons between doctors and patients, the statistic was reported as 'fair' agreement for four symptoms and 'moderate' for two.

Symptoms and effect on quality of life

Of the 43 patients in the study, 27 also completed the KDQOL-SF v1.3. There were no significant differences in the demographic characteristics and symptom scores between patients that completed the QOL questionnaires and those that did not. The common symptoms in the two groups were mostly similar.

On univariate analysis, QOL summary scores were negatively correlated with total number of symptoms as follows (Coefficient; 95%CI): KDCS (−0.96; −1.5 to −0.4); PCS (−0.57; −0.94 to −0.2) and MCS (−0.59; −0.98 to −0.2); all p values < 0.005. Similar negative correlation was seen with the number of 'major' symptoms as follows (Coefficient; 95% CI): KDCS (−2.5; −4 to −0.98); PCS (−1.56; −2.54 to −0.58) and MCS (−1.72; −2.74 to −0.7); all p values < 0.003. Using mixed-effects multi-linear regression, we created parsimonious models for the summary scores of KDCS, PCS and MCS, initially using the most common symptoms along with variables such as age, gender, dialysis vintage, Charlson's Comorbidity Score and Karnofsky Performance Index (Table 4). We used a p value of 0.2 as initial cut-off. After stepwise regression, the model for KDCS (adjusted $r^2 = 0.52$) included the symptom of poor mobility. For the PCS, the model (adjusted $r^2 = 0.5$) included poor mobility and pain. Similarly, the model for MCS (adjusted $r^2 = 0.6$) also included poor mobility and pain.

Table 3 Frequency of symptoms reported as 'major', sensitivity of recognition and agreement with patient reports

Symptom ($n = 43$)	Patients (%) reporting symptom as 'major' (95%CI)	Sensitivity – nurses (%)	Sensitivity – nephrologists (%)	Kappa statistic†: nurses	Kappa statistic†: nephrologists
Weakness/lack of energy	69 (53–82)	69	54	0.32*	0.23*
Poor mobility	44 (29–60)	68	58	0.62*	0.51*
Drowsiness	44 (29–60)	37	11	0.28*	0.11*
Difficulty sleeping	40 (24–55)	59	6	0.17	0.03
Shortness of breath	38 (22–52)	31	7	0.37*	0.07*
Pain	35 (20–49)	64	29	0.48*	0.21*
Poor appetite	30 (16–45)	38	36	0.14	0.23
Changes in skin	29 (14–42)	42	18	0.37*	0.22*
Nausea	28 (14–42)	38	0	0.37*	0.00
Itching	21 (8–34)	22	13	0.21	0.19*
Restless legs	21 (8–34)	44	0	0.29	0.00
Feeling anxious	19 (6–31)	63	14	0.32*	0.01
Diarrhoea	19 (6–31)	38	14	0.43*	0.22*
Vomiting	17 (5–28)	29	14	0.23*	0.22*
Feeling depressed	17 (5–28)	67	67	0.39*	0.55*
Mouth problems	12 (6–22)	20	0	0.13	-0.02
Constipation	10 (0–18)	0	0	-0.08	0.00

*p value < 0.05. †Interpretation of kappa statistic of agreement[25]: <0 – less than chance; 0.01–0.2 – slight; 0.21–0.4 – fair; 0.41–0.6 – moderate;0.61–0.8 – substantial; 0.81–0.99 – almost perfect.

Symptom recognition and quality of life

Patients' healthcare providers, as a whole, under-estimated symptom burden (reflected in the total symptom score in the POS-Renal) and severity (estimated as the number of symptoms scored as major). Despite this, on univariate analysis, higher total symptom scores and number of major symptoms recorded by nurses and by nephrologists were correlated with lower QOL summary scores (similar to patient-reported scores). The absolute difference per patient in the total symptom score or the number of major symptoms recorded, compared with their healthcare providers, did not influence QOL scores.

DISCUSSION

A significant burden of symptoms was observed in the haemodialysis patients participating in the study. The most common symptoms were weakness, poor mobility and drowsiness, similar to findings from other studies.[5,6,12,27] Healthcare providers did not perform well in recognizing the presence or the severity of symptoms, exhibiting low sensitivity rates and poor agreement with patient estimates.

Similar findings were reported by Weisbord and colleagues,[15] who performed an observational study of 75 patients on haemodialysis and 18 renal providers (nephrologists, nurse practitioners and nurse managers), with the aim of studying the recognition of symptoms and their severity, using the 30-item Dialysis Symptom Index.[15] They estimated that providers underreported the presence of 29 of 30 symptoms, under-estimated severity in 19 of 30 symptoms and demonstrated a sensitivity rate of <50% in 27 of 30 symptoms. Differences between nephrologists and other types of providers were not reported. Although the study was conducted in a different country and healthcare system compared with our study, the similarities in the findings are clear.

Our study extended the findings of Weisbord and colleagues by comparing nurses and nephrologists, and also by exploring the impact of symptom burden on patients' QOL. Within our healthcare setting, nephrologists are primarily responsible for symptom management, and we felt it was important to compare their recognition of symptoms with that of nurses. Additionally, we demonstrated an important consequence of persistent symptoms by showing their impact on QOL scores.

Mean summary scores (for PCS, MCS and KDCS) in our population were similar to the mean scores reported in other studies within Australia and internationally.[28,29] Higher values for 'total symptom score' or 'number of major symptoms' were both associated with a lower self-reported QOL, whether scoring was completed by patients, nurses or nephrologists. This underscores the influence of perceived and recognized symptoms on QOL in this population. Our findings are similar

Table 4 Regression models for quality of life summary scores using common symptoms

Summary score	Symptoms correlated†	Coefficient (95%CI)
KDCS ($r^2 = 0.52$)	Poor mobility	−21.68 (−31.2 to -12.2)
PCS ($r^2 = 0.50$)	Poor mobility	−11.98 (−16.91 to -7.05)
	Pain	−7.71 (−12.67 to -2.77)
MCS ($r^2 = 0.60$)	Poor mobility	−11.61 (−16.91 to -6.3)
	Pain	−8.98 (−14.2 to -3.8)

†Adjusted for age, gender, years on dialysis, Karnofsky's score and Charlson's comorbidity index.

to those of a recent study of 893 subjects, where the presence of symptoms such as pain and poor mobility had detrimental effects on health-related QOL.[12]

Nurses performed better than nephrologists in terms of sensitivity to symptoms and interrater agreement with patient estimates. This should be interpreted with caution, however, because we did not adjust for potential confounders in the patient interaction, such as the influence of gender, or the differences in duration and setting of patient contact (regular, 4 hour dialysis unit interactions for nurses *vs* the, 20 minute outpatient clinic visit with nephrologists, which occurs once in 6 to 8 weeks in our model of care). Future research could consider further investigation of the suggestion that different healthcare providers vary in their sensitivity to their patients' symptom burden.

Additionally, we studied the associations between symptom recognition and QOL scores. Within the limitations placed by the small numbers of healthcare providers and patients, it is worthwhile to note that nephrologists did not perform well in recognizing the symptoms that were significantly associated with summary scores of QOL (sensitivity for poor mobility = 54% and for pain = 29%). We could not show direct correlations between underestimation of symptoms by healthcare providers (i.e. difference between patient and nephrologist ratings) and QOL scores – this reflects the complexity of the interaction. One can anticipate that symptom amelioration is more likely to affect QOL than mere recognition.

Our study had limitations. The dialysis population studied was almost entirely Caucasian, and results may be different in other areas where linguistic or cultural barriers coexist. Nephrologists' responses could only be collected 24 to 72 h after a clinic visit. This could have contributed to underreporting of symptoms (compared with nurses) because we relied on the nephrologists' recall of patient encounters. Nephrologists spent much shorter periods of time with patients compared with nurses. However, this is a realistic representation of current models of care, mirroring how much (or little) time nephrologists have to elicit symptoms or understand QOL experiences.

An important factor limiting the generalizability of our findings and the robustness of the regression is the small sample size. These numbers are indicative of the size of our dialysis facility – in fact, over 80% of the patients consented to participate, as did 100% of the nurses and nephrologists. Additionally, only 65% of patients with recorded symptom burden could comply with the request to return the completed 81-item QOL surveys within 1 week of the symptom survey, perhaps suggesting that more time ought to have been allotted for submitting QOL data.

Despite these limitations, our study reflects actual clinical practice in a regional Australian dialysis centre, with its limited numbers of patients and healthcare personnel. Therefore, our study has important clinical implications for our current models of care, and we believe these findings need further exploration in a larger sample of patients, clinicians and participating centres. It remains to be seen if similar findings will be obtained in more urban or rural areas, which can differ widely from us in terms of the proportions of nurses and doctors to patients and the models of care employed.

The recognition of symptoms by the treating nephrologists is the first step to providing symptom relief, and there is clearly room for improvement here. We suggest that the clinical review of dialysis patients should deliberately include input from dialysis nurses. Additionally, we recommend the use of a short patient-completed symptom survey, such as the POS-Renal, during the routine outpatient review of dialysis patients. This will enable the comprehensive documentation of patients' symptoms and direct the attention of healthcare providers towards troubling symptoms more accurately.

It remains to be seen if more accurate symptom documentation will then lead to appropriate treatment, a reduced symptom burden and, subsequently, improvements in health-related QOL. Along this pathway, there are barriers to symptom recognition and to their management, and insufficient evidence that patient-reported symptom documentation improves management or reduces the symptoms themselves.[30] More likely, considering that the symptom burden is but one of the many contributors to health-related QOL, easing the symptom burden may produce only modest benefits. However, patients on dialysis already experience multiple impediments to regaining a satisfactory QOL, and any amelioration of this burden will be meaningful to the individual patient.

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3.4 Comparison of the older (≥70 years) to the younger (<70 years) population

Our sample included 43 participants, of whom 15 were over 70 years in age (Table 3-1). The Charlson comorbidity index was significantly higher (more co-morbidities) in the older group; they also had lower scores in the estimation of performance status. There was no difference in the total symptom score reported by these patients; similarly, there was no difference in the total symptom score assigned to these patients by doctors. Nurses appeared to assign more symptoms to the younger group of patients, but the relevance of this finding in our small-sized groups is not certain. There was no difference in the kidney disease, physical or mental component summaries of quality of life in the older population in this group.

Table 3-1: Comparison of older and younger patients

	Aged ≥70 (n= 15)	Aged <70 (n= 28)	*p*-value
Age (mean ± SD)	77.3 ± 5.2	52.3 ± 12.3	-
Albumin (g/L)	33.9 ± 3.5	32.6 ± 4	.31
Charlson's Comorbidity Index Score	8.9 ± 2	5.3± 3	.0002
Karnofsky Performance Score	65.3 ± 12.5	78.6 ± 10.4	.0006
Total of Symptom Score – patient reported	13.2 ± 7.5	18.7 ± 12.6	.13
Shortness of breath – patient reported (n)	2	14	.042
Total of Symptom Score – nurse assigned	10.3 ± 7.2	16.2 ± 8.6	.03
Total of Symptom Score – doctor assigned	5.1 ± 4.2	5.4 ± 5.5	.84
KDQOL – KDCS score	62.1 ± 17.1	64.8 ± 17.2	.70
KDQOL – PCS score	36.2 ± 10.2	35.6 ± 11.3	.89
KDQOL – MCS score	43.7 ± 12.9	47 ± 10.8	.52
Overall Health (self-reported)	53.8 ± 26.7	55.9 ± 30.2	.86

3.5 Symptoms in a population of conservatively managed patients

In a brief analysis, we documented the prevalence of symptoms in 35 patients (mean age 79; mean eGFR 19 ml/min). A summary of these findings is presented in Section 3.5.1, which showcases a poster presented at the annual meeting of The Australia New Zealand Society of Nephrology in 2016.

3.5.1 Patients managed with conservative, non-dialysis care: Symptoms and comorbidities

The following brief research report, appended in the form of the final manuscript, was presented as a poster at the Annual Conference of the Australasian Society of Nephrology, 2016; it has been referenced in conference proceedings as :

Raj R, Brown B; Patients managed with conservative, non-dialysis care: symptoms and comorbidities, Nephrology, 21, 177-177, 2016.

Introduction

Patients with advanced renal failure experience significant symptoms. Since 2011, we have provided supportive, non-dialysis care for patients with chronic renal impairment in a dedicated, nephrologist-led clinic. Relatively little is known about the conservatively managed population.

Aim

To describe the burden of symptoms and comorbidities in patients with chronic renal impairment (CRI) managed without dialysis.

Methods

Retrospective, descriptive study, using demographic information and biochemical test results from hospital records (2012-15). Symptoms were documented using the Patient Outcome Score - Renal survey, which allows symptom severity to be rated along a Likert scale from 0 (least) to 4 (maximum).

Standard summary scores were used to describe the data. Linear regression and student's *t*-tests were used to look for associations between age, estimated glomerular filtration rate (eGFR), biochemical variables and symptoms.

Results

Data was available for 35 individual patients (mean values: age - 79 years, eGFR - 19 ml/min). Common comorbidities (average two to three conditions per patient) included hypertension (69%), diabetes (46%), ischaemic heart disease (31%), and peripheral vascular disease (26%).

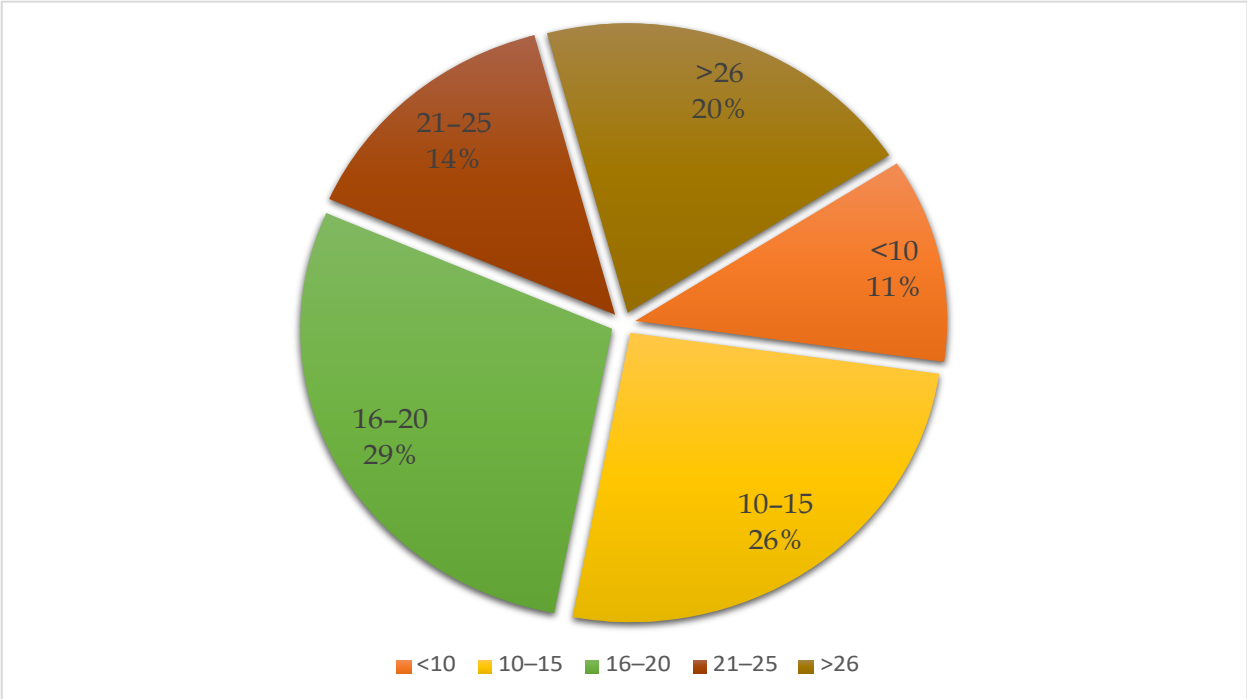

Figure 3-5: Distribution of eGFR (ml/min/1.73m²) among patients.

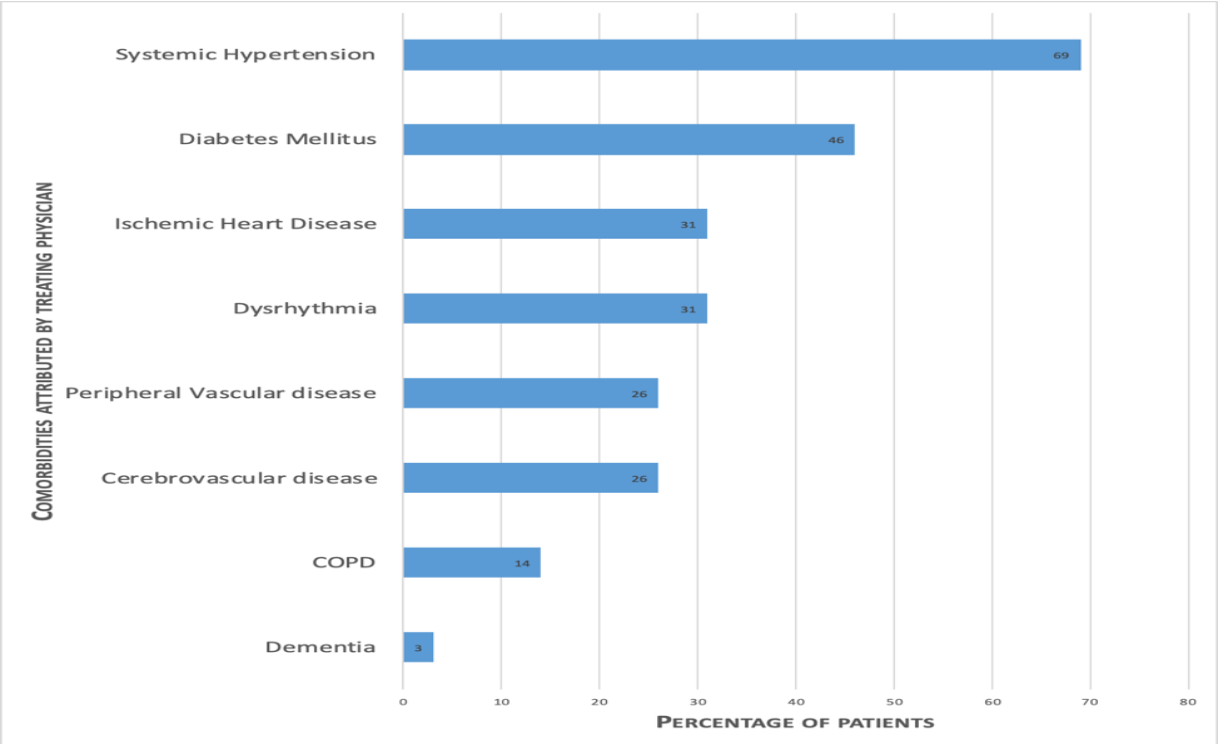

Figure 3-6: Comorbidities

The mean total symptom score was 13. On average, each patient scored four symptoms as 2, 3 or 4. Weakness, poor mobility, drowsiness and dyspnoea were the most common among the 17 queried symptoms. Age, eGFR, number of comorbidities, haemoglobin or albumin did not correlate significantly with the presence of any symptom or the total symptom burden.

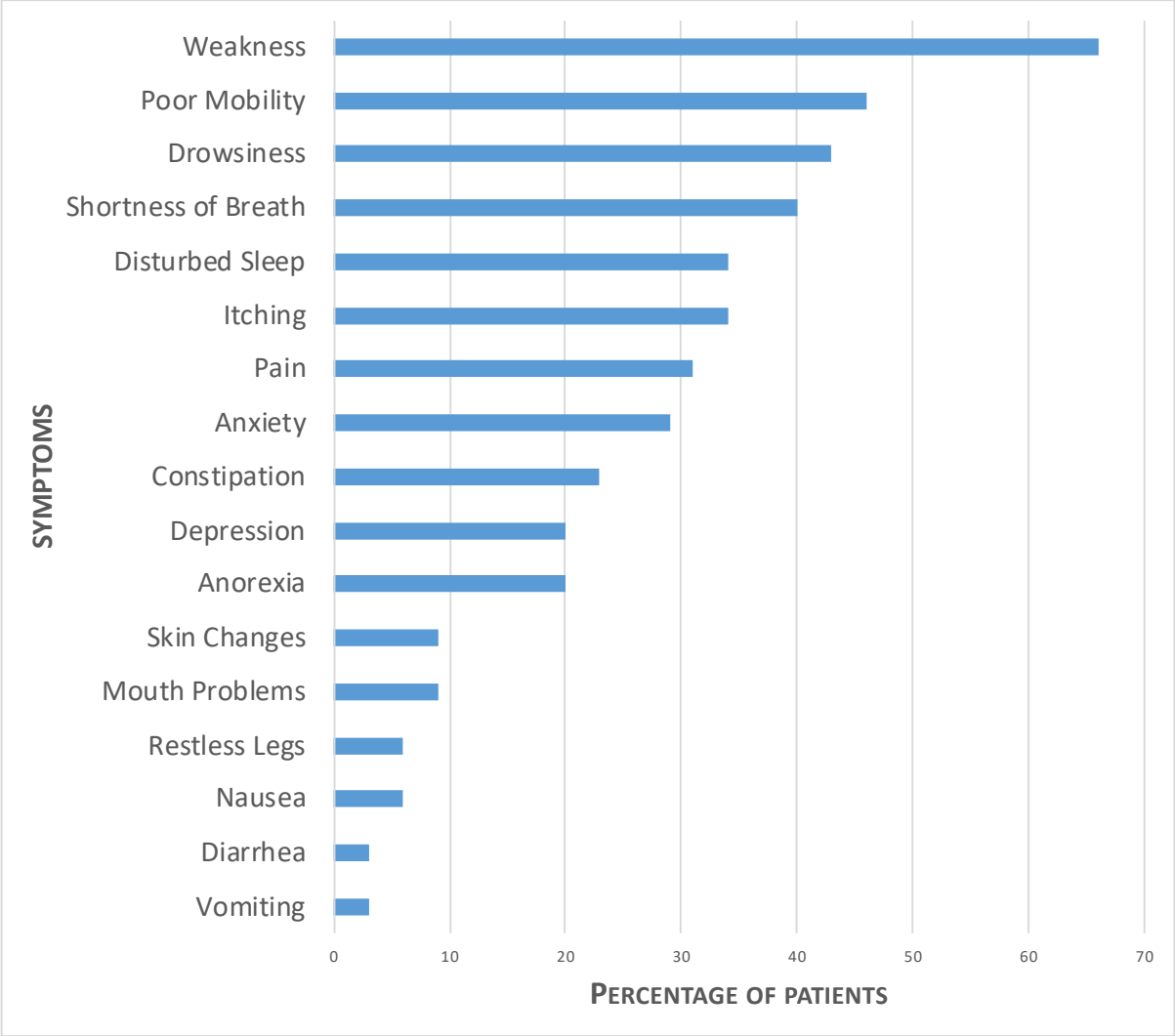

Figure 3-7: Distribution of Symptoms

Conclusion

Our results match the expected profile of the conservatively managed patient – older, and with multiple comorbidities. Such patients also suffer a significant symptom burden, similar to those on dialysis. Their complex care needs and their multiple symptoms provide clinical justification for a dedicated, multidisciplinary renal supportive care service.

3.6 Results in context

We documented a significant symptom burden in patients treated with dialysis or with conservative care. There was significant association of persistent reported symptoms with dimensions of quality of life. Patients reported, on average, at least 4 to 5 symptoms (over 17 symptoms queried) as affecting them with moderate, severe or overwhelming intensity. It must be noted here that the assignment of scores of 2, 3 or 4 as 'significant' was made arbitrarily; the survey itself has not been validated on the differences between these scores in individual patients. We intended to make sure that the presence of symptoms was captured comprehensively, but our approach carries the risk of 'over-calling' symptoms. Our reports of symptom burden are not unique - considering scores of 3 and 4 on the same survey as significant, Brennan and colleagues reported a mean number of 8.1 (±3.99) symptoms in a conservatively managed population. Similar symptom burdens have been reported internationally as well (29,59,192,195,206). Within the limitations of our small patient sample, however, we were able to show symptom burden, correlation with quality of life, prevalence of symptoms in older patients and the differences in symptom recognition between patients and healthcare practitioners – this is discussed next.

Recognition of symptoms by nurses and doctors was uniformly poor when compared to self-reported symptoms as the reference. There was low sensitivity even for the common symptoms, suggesting that despite our initial belief that the local population of dialysis patients would have their symptoms adequately recognised by their clinicians, this was not the case.

While our study suggested that our dialysis population had a significant symptom burden and that this symptom burden was negatively impacting components of quality of life, we also showed that these symptoms were poorly recognised by clinicians. This has confirmed, in a local Australian regional hospital dialysis population, that the experience of dialysis is characterised by persistent, poorly recognised symptoms which affect quality of life outcomes. This also suggests that better recognition of symptoms is a probable first step in improving symptoms and thus improving quality of life.

3.7 Transformative effects of research

As a result of these findings, we were able to influence a change of practice locally. Patients with end-stage kidney disease presenting to general nephrology clinics or to the conservative management clinics now document their symptoms using a patient-completed symptom survey. This has enabled them to report their symptoms more accurately and in greater detail. Future research will clarify if this has led to an improvement in management of symptoms or quality of life.

Chapter 4 :
Patient-reported symptom surveys

4.1 Identifying and validating a symptom survey tool in dialysis patients

Several patient-completed survey instruments are used in nephrology practice. However, not all of them are fully validated; a 2017 survey concluded that very few instruments had undergone appropriate psychometric testing, structural validation or tests for patient responsiveness and acceptability (210,211).

The IPOS-Renal survey is the most widely used survey of symptoms across renal units in Australia (212).The Cicely Saunders Research Institute at the King's College Hospital, London developed the IPOS-Renal symptoms survey for patients with renal disease as a modification of the POS-Renal symptoms survey that was in use earlier. The IPOS- Renal survey had a few advantages, including the clear separation of symptoms into physical and mental concerns, and the option for users to document, at the start of the document, what their major concerns are. It remained an easy document to complete. In light of our previous research showing poor recognition of symptoms by clinicians and the potential for patient-completed surveys to improve recognition, we undertook validation of this survey in the dialysis population in the state of Tasmania, Australia. At the time, this was the first study that validated the survey in a dialysis population (213).

4.2 Validation of the IPOS-Renal Symptom Survey in advanced kidney disease: A cross-sectional study

The following research paper has been published as :

Raj R, Ahuja K, Frandsen M, Murtagh FEM, Jose M; Validation of the IPOS-Renal Symptom Survey in advanced kidney disease: A cross-sectional study. Journal of Pain and Symptom Management; 56(2) 281-287; Aug 2018.

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DOI - https://doi.org/10.1016/j.jpainsymman.2018.04.006

(All surveys used in this research project are available online as supplementary material)

Brief Methodological Report

Validation of the IPOS-Renal Symptom Survey in Advanced Kidney Disease: A Cross-sectional Study

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Abstract

Context. The significant symptom burden in advanced renal disease is often poorly recognized by clinicians. Recently, the Integrated Palliative Outcome Score (IPOS)—renal survey was developed from pre-existing tools to capture these symptoms and other common concerns.

Objectives. We studied the validity and reliability of the IPOS-renal survey (patient and staff versions) in an Australian population.

Methods. Adult patients with advanced renal disease and nurses caring for them were participated. We initially administered the IPOS-renal survey simultaneously with other validated surveys and then retested the IPOS-renal after seven to 14 days. We tested the construct validity of 1) IPOS-renal patient version in relation to the Edmonton Symptom Assessment Survey—revised and the Kidney Diseases quality of life—short form version 1.3 questionnaire and 2) IPOS-renal staff version in relation to the Support Team Assessment Schedule survey.

Results. Eighty-one patients (65 hemodialysis, 10 peritoneal dialysis, and six on supportive care; average age 64.9 years) and 53 nurses (average renal nursing experience 10.9 years) were participated. Intraclass coefficients for test-retest reliability were >0.7 for most queries; Cronbach's alphas for internal consistency were 0.84 (patient version) and 0.91 (staff version). In tests of construct validity, Spearman's coefficient of correlation between surveys and their comparators for similar questions was significant, at 0.61 to 0.77 (patients) and 0.24 to 0.76 (staff). As expected, symptom scores and total symptom burden were negatively correlated with summary scores of quality of life.

Conclusion. The IPOS-renal surveys, patient and staff versions, have good test-retest reliability, internal consistency, and construct validity in patients with advanced kidney disease and their nurses. We recommend their use in symptom assessment. J Pain Symptom Manage 2018;56:281—287.

Key Words
Dialysis, symptoms, surveys, IPOS-renal, PROMs, validation

Introduction

Patients with end-stage kidney disease (ESKD) suffer a multitude of pervasive symptoms.[1—3] Persistent physical symptoms contribute to a lower HRQOL—both directly and indirectly through their effects on functional status, health perceptions, and feelings of subjective well-being.[4] These negative effects of symptoms on quality of life have been shown repeatedly in patients with kidney disease.[5—9] The optimal identification and appropriate management of symptoms in kidney failure have the potential to not only facilitate symptom relief but also improve the overall quality of life.

Symptom recognition by health professionals caring for these patients is often inadequate.[10,11] We have

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previously shown that when doctors and nurses rely on standard consultations with patients in outpatient clinics or dialysis facilities, they demonstrate poor sensitivity to patients' symptoms and only "weak" agreement with their ratings of severity.[5] Similar findings have also been shown in a North American health care setting.[12]

Symptom surveys that are completed by patients and then passed on to clinicians are potential solutions to bridge this gap.[13] Recommendations by the Australia New Zealand Society of Nephrology support these patient-completed surveys as enhancements to comprehensive care.[14]

An optimal patient-reported outcome measure (PROM) ought to be easy to administer, short, relevant to kidney disease, and sensitive to change. Several patient-reported measures are widely used, despite limited validation data.[15,16] A national survey of nephrology units across Australia found that while the majority collected patient-reported data, the most popular instrument used was the IPOS-renal symptom survey—a relatively new tool that has not yet been adequately validated (ANZDATA Working Group on PROMs 2017; unpublished data).

The IPOS-renal is part of a suite of PROMs developed in the U.K. The original Palliative Outcome Score (POS) and subsequently, a symptom module, the POS-symptoms (POS-S), and finally, the generic IPOS tool (a synthesis of the POS and POS-S) were developed for the comprehensive assessment of patients with advanced disease and receiving palliative care.[17–22] The kidney disease–specific surveys, initially the POS-renal and later the IPOS-renal, were developed based on the POS and IPOS palliative care surveys, but with the additional inclusion of symptoms common in chronic kidney disease such as pruritus and restless legs.[23,24] These surveys offer staff- and patient-completed versions assessing the same domains. Although the generic questions in the survey have been tested for content validity and face validity, construct validity of the IPOS-renal in population with advanced kidney disease has not been established. We conducted this study to assess the reliability and construct validity of the IPOS-renal (patient and staff versions) in an Australian population of patients with advanced kidney disease and the nurses who care for them.

Materials and Methods

IPOS-Renal Patient Version

Study Population. We included a convenience sample of adult (>18 years) patients with advanced kidney failure (estimated glomerular filtration rate [eGFR] < 15 mL/minute/1.73 m^2 on two occasions 3 months apart) who were treated with either hemodialysis/peritoneal dialysis or with conservative, nondialytic management in a renal supportive care clinic. Participants were recruited from outpatient clinics or dialysis services at two regional hospitals in Tasmania, Australia. Exclusion criteria included those clinically assessed by treating nurses to be cognitively impaired or too unwell to participate. Patients completed these surveys independently or with help from their carers.

Survey Instruments. Participating patients completed the IPOS-renal, the Edmonton Symptom Assessment System–revised (ESAS-r), and the Kidney Diseases Quality of Life–Short Form version 1.3 (KDQOL-SF v1.3) (see Table 1).

Procedures. Demographic data collected for patient participants from their medical record included age, gender, and physician-assigned comorbid conditions. The Charlson Comorbidity Index was assigned based on the comorbidities.[31]

Survey data collection occurred at two time points, concurrently for patient and staff participants. Different survey instruments were used at each time point, as shown in Table 2. At the second time point, which was 7 to 14 days after the first surveys had been completed, patient participants repeated the IPOS-renal survey and also indicated if "their condition had changed" by answering "yes" or "no" to a direct question. Patients on hemodialysis completed these surveys during a dialysis session, whereas those on peritoneal dialysis or conservative care completed them during routine outpatient visits initially and then mailed in completed surveys from home for the follow-up IPOS-renal survey.

Data Analysis. Demographic data were reported using descriptive statistics. We tested for reliability and validity as follows (all statistical analysis was done with Stata® v 12, StataCorp LLC, Texas).

Tests of Reliability. Test-retest reliability using intraclass correlation coefficients (ICCs) was calculated between the repeated IPOS-renal surveys in stable patients—that is, those patients for whom, at Time Point 2, patients answered "no" to the question: "Has your condition changed?". ICC estimates and their 95% CIs were calculated based on a mean-rating (k = 2), absolute-agreement, two-way mixed-effects model.[32] Internal consistency was tested by estimating Cronbach's alpha.

Tests of Validity. In testing for convergent validity, we hypothesized that there would be a positive correlation between similarly worded items on the IPOS-renal and the ESAS-r surveys and a negative

Table 1
Survey Instruments and Scores Used in the Study

Survey Instrument	Details	Comments
IPOS-renal (patient and staff versions)	Patient and staff use; 10 questions including 23 subitems covering physical and psychological symptoms, carer anxiety, and practical issues; plus, optional items for any other concerns; scored on a Likert scale from 0 to 4 for increasing severity; total score reflects symptom burden.	Derived from the validated generic IPOS survey, itself a synthesis of POS and POS-S surveys.[24,25] Most widely used PROM as per a 2017 survey of Australian renal units (unpublished data).
ESAS-r	Patient-completed; 10 items querying physical and psychological symptoms; Visual Analogue Scale with scores from 0 to 10; total score reflects symptom burden.	Cross-sectional and longitudinal validity established in a renal disease population.[7,26]
KDQOL-SF v1.3	Patient-completed; assesses HRQOL; includes 36 generic core questions and 48 specific renal-related questions, encompassing symptoms, burden of renal disease, and effects on daily life; allows calculation of summary scores—KDCS, PCS, and MCS.	Developed from the SF-36 specifically for patients with renal disease; validated in dialysis and renal transplant populations; too long for routine outpatient use.[27,28]
STAS	Staff-completed; 16 items covering physical, psychosocial, spiritual, communication, planning, family concerns, and service aspects	Designed for treating staff to assess clinical and intermediate outcomes in palliative care; widely used and validated.[22]
AKPS	Staff-assigned measure of the patient's overall ability to perform activities of daily living as observed by a clinician. It is a single score between 10 and 100; decreasing numbers indicate a reduced performance status and vice versa.	Serial scores can be used by staff to monitor clinical progress.[29]
Phase of illness	Staff-assigned categories that characterize how unwell a patient is; categories include stable, unstable, deteriorating, and terminal.	Has been used as a predictor of cost in the Australian health care setting.[30]

IPOS = Integrated Palliative Outcome Score; ESAS-r = Edmonton Symptom Assessment System—revised; KDQOL-SF v1.3 = Kidney Diseases Quality of Life—Short Form version 1.3; KDCS = Kidney Disease Component Score; PCS = Physical Composite Score; MCS = Mental Composite Score; STAS = Support Team Assessment Schedule; AKPS = Australia-modified Karnofsky Performance Scale.

correlation between the IPOS-renal and the composite scores of kidney disease burden, and physical and mental QOL on the KDQOL-SF v1.3 survey. Convergent validity was ascertained by testing the Spearman's correlation coefficient.[33] Divergent validity was explored by testing the correlation between symptom scores and QOL subscales on separate surveys—we hypothesized that there would be only weak correlations between items that were not directly related.

We checked for sensitivity to change by comparing IPOS-renal scores at Time Point 1 and Time Point 2 using the Wilcoxon signed-rank test, among patients who indicated that their clinical condition had changed at Time Point 2.

Table 2
Surveys/Scores Completed by Participants at Different Time Points

Time Points	Patients	Staff
Time Point 1: day of initial participation	• IPOS-renal • ESAS-revised • KDQOL-SF v1.3	• IPOS-renal • STAS • AKPS • Phase of illness (two staff members per patient)
Time Point 2: 7 to 14 days later	• IPOS-renal	• IPOS-renal • AKPS • Phase of illness (one staff member per patient)

IPOS = Integrated Palliative Outcome Score; ESAS = Edmonton Symptom Assessment System; KDQOL-SF v1.3 = Kidney Diseases Quality of Life—Short Form version 1.3; STAS = Support Team Assessment Schedule; AKPS = Australia-modified Karnofsky Performance Scale.

IPOS-Renal—Staff Version

Study Population. For staff participants, we recruited from registered nurses who were directly involved in the care of the participating patients in hemodialysis, peritoneal dialysis, or renal supportive care clinics. We ensured at least two nurses per patient; one nurse could report on multiple patients.

Survey Instruments. Participating staff completed two surveys at initial participation on the same day as the patient—the IPOS-renal (staff version) and the Support Team Assessment Schedule (STAS). Seven to 14 days later (on the same day as the patient), one nurse per patient completed a second IPOS-renal staff version survey. In addition, staff scored patients on the Australia-modified Karnofsky Performance Scale and the Phase of Illness Scores on both occasions (see Table 1).

Procedures. Demographic data collected about participating staff nurses included age, gender, and years of experience in renal nursing.

Procedures were similar to those in the patient group of participants, other than differences in the instruments used (Table 2). Surveys were completed on the same day as patients at both time points (7 to 14 days apart). At the second time point, staff also noted "yes" or "no" to the question—"Has your patient's condition changed?". Staff participants completed the surveys in the dialysis or outpatient clinics at both time points.

Table 3
Characteristics of the Patients in the Study Population

Characteristics	$N = 81$	%
Age in yrs (mean ± SD)	64.9 ± 13.3	
Gender		
Male	45	56
Female	36	44
Diabetes	23	28
Ischemic heart disease	30	37
Charlson Comorbidity Index (mean ± SD)	4.5 ± 2.6	
Treatment modality		
Hemodialysis	65	81
Peritoneal dialysis	10	12
Conservative care (mean eGFR 10 mL/minute)	6	7

eGFR = estimated glomerular filtration rate.

Data Analysis. Analysis methods were similar to those described for patients mentioned previously. We estimated test-retest reliability between repeated surveys of patients whose condition staff participants reported as unchanged. To test convergent validity, we compared similarly worded questions on the IPOS-renal (staff version) and the STAS surveys.

Results

IPOS-Renal—Patient Version

Eighty-one patients participated in the study—65 patients treated with hemodialysis, 10 patients with peritoneal dialysis, and six patients with renal supportive (nondialysis) care. The average age of participants was 64.9 years; 56% of patients were male. Other demographic details are listed in Table 3.

Tests for Reliability. Of the 81 participants, 69 (85%) completed the second IPOS-renal survey—among them, 56 reported no change in their status between the two time points. Intraclass coefficients demonstrating test-retest reliability showed "good" correlation (0.75–0.9) for 13/23 of the survey questions and "moderate" (0.5–0.75) for 8/10 of the remaining ones (see Table 4).[32–34] Cronbach's alpha for determining internal consistency was 0.84 for the questionnaire, showing good consistency.[32–34]

Tests for Validity. In testing for convergent validity, we compared the IPOS-renal with corresponding items on the ESAS-r and with summary scores on the KDQOL-SF v1.3 (see Table 5). "High-to-moderate" correlations (Spearman correlation coefficient values of 0.61–0.77, $P < 0.05$) were seen for total symptom burden scores and for all individual items that queried the same domains in the IPOS-renal and ESAS-r surveys.

As hypothesized, there was a statistically significant negative correlation between the total symptom burden and the composite QOL scores of Kidney Disease Component Score, Physical Composite Score, and Mental Composite Score, as measured by the KDQOL-SF v1.3. Several individual symptom scores were also negatively correlated with these summary quality of life scores, with the strength of the correlation ranging from "moderate" to "high."

In checking for divergent validity, we saw that items on the IPOS-renal that were not questions about symptoms (such as "have practical problems been addressed" or "has time been lost on appointments") showed no correlation with the physical or mental composite scores of QOL (data not shown). The sample size was not sufficient to estimate sensitivity to change.

Table 4
Test-Retest Reliability: Mean Intraclass Correlation Coefficients (ICCs) Between First and Subsequent IPOS-Renal Surveys in Stable Patients ($n = 56$; all $P < 0.05$)

Symptoms/Questions	Patient Version	Staff Version
Pain	0.89	0.84
Shortness of breath	0.77	0.76
Weakness or lack of energy	0.84	0.69
Nausea	0.88	0.74
Vomiting	0.79	0.7
Poor appetite	0.76	0.4
Constipation	0.72	0.54
Sore or dry mouth	0.79	0.68
Drowsiness	0.78	0.72
Poor mobility	0.79	0.83
Itching	0.79	0.55
Difficulty sleeping	0.72	0.66
Restless legs	0.83	0.73
Changes to skin	0.64	0.73
Diarrhea	0.75	0.23
Anxiety	0.52	0.62
Family/friends anxious about you	0.72	0.63
Depressed	0.71	0.78
Felt at peace	0.73	0.74
Able to share with family/friends	0.48	0.67
As much information as you wanted	0.59	0.4
Practical problems addressed	0.78	0.58
Time wasted on appointments	0.35	0.68
Total symptom score	0.84	0.72

Interpretation of ICC values: <0.5 poor reliability, 0.5–0.75 moderate reliability, 0.75–0.9 good reliability, >0.90 excellent reliability.[32]

IPOS-Renal Staff Version

Fifty-three staff nurses participated in the study, of which 47 were female and six were male. Their mean age was 47 (SD: 10.5) years. On average, staff participants had spent 21 (SD 11.9) years as a nurse and 10.9 (SD 8) years as a renal nurse.

Tests of Reliability. Test-retest reliability was checked in those staff surveys where no change in the patient's condition was reported ($n = 42$). Intraclass coefficients showed "moderate" (0.5–0.75) or "good" (0.75–0.9) reliability for 20 of 23 items on the survey[32] (see Table 4). Cronbach's alpha for the staff version was 0.91, showing excellent internal consistency.

Table 5
Convergent Validity: Spearman Correlation Coefficients Between the Patient-Completed Surveys and Summary Scores of Quality of Life (in Bold Text Where $P < 0.05$)

Symptom Surveys		KDQOL-SF v1.3 Summary Scores		
IPOS-Renal	ESAS-r	KDCS	PCS	MCS
Pain	**0.77**	**−0.49**	**−0.59**	**−0.52**
Shortness of breath	**0.76**	**−0.29**	**−0.38**	**−0.28**
Weakness or lack of energy	**0.65**	**−0.51**	**−0.63**	**−0.4**
Nausea	**0.65**	**−0.33**	**−0.28**	**−0.28**
Vomiting		**−0.13**	**−0.28**	**−0.2**
Poor appetite	**0.67**	**−0.49**	**−0.33**	**−0.35**
Constipation		**−0.27**	**−0.21**	**−0.03**
Sore or dry mouth		**−0.18**	**−0.21**	**−0.11**
Drowsiness	**0.67**	**−0.44**	**−0.4**	**−0.31**
Poor mobility		**−0.44**	**−0.55**	**−0.37**
Itching		**−0.29**	**−0.31**	**−0.16**
Difficulty sleeping		**−0.45**	**−0.3**	**−0.36**
Restless legs		**−0.39**	**−0.33**	−0.2
Changes to skin		**−0.42**	**−0.28**	**−0.32**
Diarrhea		−0.2	−0.17	**−0.24**
Anxiety	**0.61**	**−0.56**	**−0.28**	**−0.6**
Family/friends anxious about you		**−0.45**	**−0.3**	**−0.36**
Depressed	**0.68**	**−0.44**	**−0.26**	**−0.54**
Felt at peace		**−0.03**	−0.19	−0.22
Able to share with family/friends		−0.03	−0.2	−0.04
As much information as you wanted		0.05	−0.06	−0.06
Practical problems addressed		**−0.27**	−0.18	**−0.28**
Time wasted on appointments		**−0.29**	−0.23	**−0.26**
Total symptom score	**0.65**	**−0.65**	**−0.59**	**−0.6**

KDQOL-SF v1.3 = Kidney Diseases Quality of Life−Short Form version 1.3; IPOS = Integrated Palliative Outcome Score; ESAS-r = Edmonton Symptom Assessment System−revised; KDCS = Kidney Disease Component Score; PCS = Physical Composite Score; MCS = Mental Composite Score.
Interpretation of Spearman correlation coefficient: 0.9−1, very high correlation; 0.7−0.9, high; 0.5−0.7, moderate; 0.3−0.5: low; 0−0.3, negligible correlation; negative values indicate inverse correlation.[33]

Tests of Validity. We determined the construct validity by comparing IPOS-renal (staff version) with scores on the validated STAS survey. Spearman's correlation coefficients for answers to similarly worded questions showed statistically significant correlation, with the strength of correlation being "moderate," as follows (all P values < 0.05): pain (0.76), symptoms other than pain compared to total scores for symptoms other than pain (0.71), patient anxiety (0.65), family anxiety (0.65), and time wasted (0.75).

Divergent validity was demonstrated by the lack of correlation between unrelated items on the IPOS-renal and STAS surveys (data not shown).

Discussion

Unlike traditional biophysical measures, PROMs such as the IPOS-renal allow the clinician to capture the patient's subjective illness−related concerns.[35] Validation of the psychometric properties of such an outcome measure is valuable to clinicians, researchers, and health administrators. The paucity of validation studies specifically involving the IPOS-renal could be considered a disadvantage, and our study sought to rectify this.

Important aspects of psychometric validation include tests of reliability (i.e., the extent to which the scores are consistent, typically tested as test-retest reliability and internal consistency), validity (i.e., the accuracy of the assessment in measuring what it is supposed to—studied as content, criterion, and construct validity), and sensitivity to change.[32−34] Our study of the patient and staff versions of the IPOS-renal demonstrated good test-retest reliability and internal consistency, suggesting that the survey is reliable in both versions. In stable patients, the ICC values for test-retest reliability were in the range "poor" for only two items—"ability to share with family or friends" and "time wasted on appointments." Both these items may well vary periodically, depending on the opportunities to meet social contacts or the requirement to go to medical appointments. Similarly, "poor" test-retest reliability was seen in the staff versions for the items addressing diarrhea and information received by patients. Staff surveys in our study were completed without asking the patients or their carers direct questions, and reliability may improve if tested in everyday situations where staff members interact freely with patients and carers.

Face and content validity (i.e., the survey addresses the concerns it is supposed to measure) in a patient population has already been shown for the questions in the survey.[17−20] Criterion validity (i.e., the survey correctly predicts symptoms) is difficult to test in the absence of a "gold standard" for symptom elicitation. We tested two aspects of construct validity—namely, convergent (i.e., presence of correlation between item scores that measure the same construct) and divergent validity (i.e., lack of correlation between scores for unrelated items). The patient survey, compared with other validated symptom and quality of life surveys, showed satisfactory convergent validity. We also showed, as expected, that higher symptom burden reflected in the IPOS-renal survey correlated with lower physical and mental composite scores, further establishing construct validity. Similarly, we were able to demonstrate construct validity for the staff version when compared to the STAS survey. Feedback from staff participants who used the survey was positive, with the staff version being described as easy to understand and score. Both patient and staff versions showed that when unrelated items were compared in different surveys, the correlation was poor, showing divergent validity. Our study was not sufficiently powered to detect sensitivity to change or differences between patient groups.

Patients' reluctance to mention their problems and clinician ignorance about symptoms remain

important barriers to improving their management in hemodialysis patients.[1,10] Patient-reported symptom surveys such as the IPOS-renal are a potential solution to bridge this gap. The IPOS-renal survey has features that recommend its use over other similar surveys. It is short and easy to complete, and its domains also span concerns relevant to chronic disease such as information needs, carer anxiety, time wasted on appointments, and other practical issues. It invites patients to use free text to list their most important problems first, so that clinical attention can focus specifically on issues that matter most to the patient. It also provides space to record other symptoms that may not be included in the survey.[21] Its popularity across units in Australia, where it is used for both clinical management and for research, suggests that clinicians are already finding the survey useful in practice (ANZDATA Working Group on PROMs 2017; unpublished data). A further advantage is that the staff version of the IPOS-Renal may be helpful in situations where patients become too ill to report their problems.

The study had limitations. We chose a convenience sample of patients and their nurses; most of our participants were on hemodialysis, with smaller numbers on peritoneal dialysis or supportive care. We could not achieve sufficient participant numbers to report sensitivity to change. While some patients completed surveys within the dialysis unit, others completed them at home or in outpatient clinics. A study powered to detect significant changes in symptom scores, and with a more deliberate sampling of patients treated with peritoneal dialysis and supportive care, will address some of these limitations.

Conclusion

In our study population, the IPOS-renal symptom survey, patient and staff versions, demonstrated good internal consistency and test-retest reliability. Convergent validity was also established by comparison to other established surveys administered concurrently. Our results recommend the use of this survey for the documentation of symptoms in patients with advanced kidney disease.

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Dr. Raj, Dr. Ahuja, Dr. Frandsen, Dr. Murtagh, and Dr. Jose declare they have nothing to disclose in terms of conflict of interest relevant to this article.

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Chapter 5: Exploring outcomes in the elderly on dialysis

5.1 Overview

5.1.1 Qualitative analysis

Older patients appear to adapt to dialysis in different ways. While some patients adapt well and seem to thrive, others tend to deteriorate. If these outcomes could be predicted in advance, this would benefit patients and families that are considering treatment options for end-stage kidney failure. We do not have satisfactory methods of predicting these outcomes - in fact, as discussed, most prognostic scores focus on survival outcomes. This qualitative study was designed to explore outcomes on dialysis from the point of view of the older patients' perceptions about life on dialysis - specifically, the concepts regarding a 'good outcome', and what they considered were the factors leading to such outcomes.

Qualitative research, using the phenomenological approach, attempts to study the experiences of a phenomenon from the points of view of the participants themselves (214). The semi-structured interview format allows the interviewer to initiate and direct the flow of the interview, but because these questions are open-ended, they allow the participant to freely express themselves as they provide their recount of their experiences. Once interviews are recorded and transcribed, the transcripts then provide the researcher a rich source of material for analysis.

With the aim of understanding the outcomes that are relevant to older patients, we chose a group of participants over the age of 70 who had already started dialysis

treatment. Our area of interest was the description of experience. Moving beyond the assumption that survival is the only important outcome, we wanted to explore what patients on dialysis thought were the other important outcomes.

In addition, we also wanted to explore the influence of patient-specific characteristics on how outcomes of dialysis were perceived. Specifically, we wanted to study the influences of illness perception and personality, as detailed below.

5.2 Enabling good outcomes in older adults on dialysis: A qualitative study

This qualitative study has been submitted to medical journals for publication and is under consideration, as:

Raj R, Brown B, Frandsen M, Ahuja K and Jose M; "Enabling good outcomes in older adults on dialysis: A qualitative study".

The following is a Word document version of the final submission proof.

See Appendix for interview guide and reporting guidelines checklist.

5.2.1 Abstract:

Background:

Older individuals, the fastest growing subset of patients on dialysis, do not always have optimal outcomes on treatment, particularly with regards to quality of life. While previous research has focused on their survival, less is known about factors influencing other positive outcomes. Such information can guide decision-making around dialysis initiation and potentially improve outcomes for patients already on dialysis. This article describes the use of qualitative research methods to explore these factors from the perspective of elders already on dialysis.

Methods:

Semi-structured interviews with participants aged over 70, receiving dialysis at a regional Australian hospital, were recorded and transcribed. From participants' responses, we identified descriptive themes using a phenomenological approach, with verification by two researchers. Factors affecting outcome were derived reflexively from these themes.

Findings:

17 interviews (11 male; mean age 76.2 years) were analysed prior to saturation of themes. Experiences of dialysis were described across four domains - the self, the body, effects on daily life and the influences of others; yielding themes of (i) responses to loss (of time, autonomy, previous life), (ii) responses to uncertainty (variable symptoms; unpredictable future; dependence on others), (iii) acceptance / adaptation (to life on dialysis; to ageing) and (iv) the role of relationships / support (family, friends and clinicians).

Conclusion:

Outcomes other than survival could be influenced by symptoms, physical status, psychological adaptation, social factors and availability of support. Appropriate pre-dialysis education is needed, including information about lifestyle changes and restrictions. Once on dialysis, encouraging active adaptation to treatment and to ageing, with family and clinician support, could improve outcomes.

5.2.2 Introduction

By 2030, it is estimated that 4 to 7 million people will be receiving renal replacement therapy worldwide (215). Those over the age of 75 make up 22% of all patients on dialysis in Australia (31), and figures are similar elsewhere (USA – 20%, UK - 16% and Japan - 31% (216–218). The elderly, particularly if they have comorbidities, often do not derive benefit from dialysis - both in terms of mortality and quality of life (12,219). This suggests that comprehensive conservative or supportive care, without dialysis, may be a valuable treatment pathway for such patients.

It is common for the older patient with advanced renal failure to frame the choice between dialysis therapy or conservative care as a choice between life (dialysis) or death (non-dialysis pathway) (220). Clinicians can access several recommended tools to predict prognosis in elderly patients with advanced renal failure (128). While these prognostic tools often consider survival, they may not predict quality of life or other outcomes, which may arguably be more important in these elders' lives (221). The intrusive nature of dialysis treatment alters multiple aspects of daily life, including the effects on physical and cognitive states, and the worsening of the complexities of ageing (222). Information about these effects could be used by older adults choosing between

dialysis and conservative care, or be used to suggest interventions to improve outcomes for patients already on dialysis (223).

In adapting to a major illness, the older patient is likely to have different priorities and coping strategies compared to their younger counterparts (224). After starting dialysis some older patients appear to thrive, while others enter a progressive spiral of deterioration, dependency and repeated hospitalisation (58). These qualitative and individual consequences of dialysis are hard to predict. In order to understand factors influencing these outcomes, distinct from survival or mortality, we considered that an exploration of the patient's perspective would yield useful insights (225). In this article, we report the results of a qualitative research study that used semi-structured interviews to document older patients' experiences of dialysis and outcomes.

5.2.3 Methods

Study population, recruitment and sampling

A convenience sample of eligible participants was recruited from among patients under the care of a regional Australian hospital. Participants were eligible to participate if they were aged over 70 years and were being treated with haemodialysis or peritoneal dialysis for more than three months. Exclusion criteria included patients judged by their treating physician to be too unwell or cognitively impaired to participate; and patients unable to converse in English. The research protocol was approved by the Tasmanian Human Research Ethics Committee (H0014515).

Potential participants were invited to the study by the research nurse in person, provided information sheets and given the opportunity to read and ask questions of the study. Interested participants were then asked to sign a consent form. Face-to-face interviews were conducted at a time and place convenient to the participant. Interviews

lasted approximately 45 minutes (range 30 to 75 minutes) and were audio recorded. Demographic data collected included age, gender and years spent on dialysis.

Interviews

Questions for the semi-structured interviews were derived from informal email surveys of experienced nurses and nephrologists prior to starting the research project (see Table 5-1). The interviews were conducted face-to-face by a female registered nurse of 12 years' nursing experience, trained in conducting qualitative research interviews. Only the research nurse and participant were present at the interviews. Most interviews (14 of 17) were conducted in participants' homes; 3 interviews were conducted in a private room at the dialysis unit.

(The questions, recording equipment and transcription services were pilot-tested on a volunteer dialysis patient who was aged 52, and therefore not eligible for inclusion in the study).

Table 5-1: Interview questions derived from an informal survey of doctors & nurses

Interview questions	Expected areas of interest for the study
1.How are you doing on dialysis, and why?	What do patients think influences their outcomes?
2. How do the people around you influence you - at home, or in the renal unit (doctors, nurses or other patients)?	Do the people around the older patient influence outcomes?
3. How dependent / independent are you for: activities of daily living; other practical things (money, food, transport)? Who helps?	Does being independent of others describe a good outcome?
4. What are the best & worst things about life (on dialysis & overall)?	Are there overwhelming positives and negatives to being on dialysis?

Interview questions	Expected areas of interest for the study
5. How do you see yourself if you were not on dialysis?	How much has dialysis impacted on life course?
6. What are your thoughts regarding the future or advance care planning?	What are the roles of hope, optimism or pragmatism?

Data analysis

All interviews were audio-recorded and transcribed verbatim by external professional transcribing services (Outscribe Transcription Services, Australia). Transcripts were cross-checked for accuracy, and participants were offered the opportunity to read over their transcripts for accuracy (all declined). Transcribed interviews were then imported into data analysis software (NVivo qualitative data analysis Software; QSR International Pty Ltd., Australia. Version 10, 2014) to enable rigorous, low-error analysis of the transcribed text. The purpose of the analysis was to explore and describe the individual experiences and opinions of the participants with regards to dialysis treatment. A phenomenological approach was adopted, and iterative thematic analysis utilised to develop representative themes from the text.

Primary analysis of transcripts was conducted by author RR, utilising line-by-line coding to identify key concepts and issues. Codes / concepts were then grouped into themes and categorized. A memo and project log were kept throughout this process. Supplementary analysis of the data by author MF was conducted to verify themes and domains identified by RR (18). Throughout this process there was reflexive consideration of the analysis and discussion between the two investigators (19,20). Key domains and major themes were identified via consensus of the authors. Interviews were conducted and analysed until there was saturation of themes, achieved after 17 participants were interviewed. Finally, potential predictive factors of outcome on

dialysis were derived from the described experiences and themes by authors RR and MF.

5.2.4 Findings

Transcripts from 17 interviews were analysed prior to saturation of themes. The mean age of participants was 76.2 years (range: 70 to 83); on average, they had spent 4.3 years on dialysis (range: 2 to 9 years). Eleven participants were males, and 6 females. None of the participants were employed.

Participants' reports of their experience of dialysis and its effects could be classified under four main domains: (i) the concepts of self, (ii) the physical body, including symptoms, (iii) effects on everyday life and (iv) participants' relationships with others. These descriptions are discussed in detail below.

Dialysis and the Self

> *"I don't know, I've forgotten what it's like not to be on dialysis".*
>
> *[P7, Female, 75]*

Dialysis was described as a very intrusive treatment, which had a significant impact on the concept of self, caused major changes in lifestyle and altered the life-roles of most participants. There was acknowledgement that undergoing treatment was necessary to preserve life and the self. The decision to start dialysis and subsequently to continue it, despite discomfort, was framed as a choice between living and dying, since participants interpreted that without dialysis, death was certain. Even though dialysis was 'chosen' as a treatment option, there was ambiguity about whether there was choice after all, since there really was no other option if the person wanted to stay alive.

"…no well I've got, well I've got a choice. I can have dialysis or go up the chimney!"

[P5, Male, 75]

Being on dialysis altered how some participants thought about good outcomes in their lives. When replying to questions about how they were doing on dialysis, some participants tended to frame themselves in terms of their illnesses and responses to treatment. For instance, they said that dialysis sessions without interruptions or medical problems indicated that they were having a good outcome. Similarly, 'good' biochemical test results, trouble-free machine behaviour, or positive reports from healthcare professionals implied positive outcomes for some, suggesting a shift from internal to external, 'medicalized' determinants of one's status.

When asked about the reasons for their perceived good outcomes, participants cited their own personal factors. Prominent among these descriptions was the characterisation of themselves as independent entities that regained control over life's events. Several participants described themselves as 'stubborn', 'obstinate' or 'a fighter'. These narratives about control over life's events was the most frequently coded theme. A personality that remained independent yet adapted to adversity and carried on was cited as a reason for doing well on dialysis.

"Yeah. I'm just one of those people that feel you've got to, you know, get on with life and get on, you know, if you've got a problem, just deal with it yourself".

[P4, Male, 78]

Participants highlighted the importance of a positive attitude which enabled them to bear the difficulties of dialysis and ageing. Such an attitude was demonstrated in their refusal to worry about things, to take things in their stride, or in acknowledging that

"the only one to help me is myself". Participants spoke of never 'thinking negative'. As one participant said, there's "no point worrying it".

> *"I don't let anything worry me, and I take everything in my stride, I don't go sulking to somebody about this or about that, I just put up with it all. And [my nurse] says, you've got a good attitude".*
>
> *[P6, Female, 75]*

In response to questions about the future, the older age of participants in this study was reflected in their attitudes towards mortality and death . Several participants demonstrated a pragmatic approach; they acknowledged that life was limited, and some declared that they did not fear death.

> *"Just wait for the sun to rise the next day and we'll live that one as it comes. That's all you can say. Because we don't know how long we've got…..I don't think I've got that much left, really. Too bad to worry about it now".*
>
> *[P4, Male, 78]*

Whereas all patients acknowledged the difficulties of living on dialysis treatment, only some patients were convinced that they were not doing well at all. Others described adapting successfully and valued the lives they led on dialysis, despite all the difficulties. They accepted the necessity of dialysis treatment and adjusted their lives around the treatment, sometimes calling on family or healthcare personnel to help in their transition. For some such patients, stopping treatment and accepting eventual death was considered "giving up" of a valuable life.

> *"Oh, life's too valuable to turn around and do a silly thing like that. Throw the sponge in like that, just get sick of it like that…"*
>
> *[P2, Male, 73]*

Dialysis and the Body

> *"Well, it's hard to define because I have a problem – like, renal problem – right? And I also have an old age problem."*
>
> *[P12, Male, 83]*

Our participants frequently mentioned the effects of persistent symptoms and progressive physical deterioration, compounded by the effects of growing older. This impacted on their ability to do things they had done earlier - a loss felt by several participants. Progressive loss of vision, worsening mobility and persistent fatigue were among the problems mentioned. Participants reported being now unable to read, drive or do things around the house unaided.

> *"Just doing me housework and all that, you know. I used to do everything all at once, now I can't. Getting old."*
>
> *[P6, Female, 75]*

Not all participants had relief from bodily symptoms after starting dialysis, and this led to contrasting perspectives regarding symptoms and their impact on the experience of dialysis. On the one hand, a subset of interviewees remembered being severely symptomatic with renal failure prior to beginning regular dialysis treatments and were grateful that starting therapy made them feel much better. They continued dialysis, despite its difficulties, because they did not want to once more feel as bad as they had prior to the initiation of dialysis.

> *"And I feel a lot better than what I did. But if you could have seen me before I got on dialysis, it was dreadful. Yeah."*
>
> *[P8, Female, 71]*

On the other hand, there were others who developed a new set of symptoms as a result of the dialysis procedure itself - intolerance of fluid removal, the pain and uncertainty

around inserting needles into the arteriovenous fistula (used for hemodialysis access) and the need to sometimes rest in bed for long periods after each dialysis session. The symptoms were unexpected for some patients, who had expected that dialysis would actually make them feel better.

> *"Well everybody tell me I'll feel real good after it, but you don't…No they told us that you know first off they said you'll feel better and everything but you don't."*
> *[P1, Male, 78]*

A third group of participants had pre-existing bodily symptoms from other illnesses - such as low back pain, or diabetic complications - which did not improve, and even worsened the experience of dialysis. Patients troubled by worsening physical status, and a severe symptom burden, often stated that they were not doing well on dialysis.

Dialysis and its Effects on Daily Life

Participants reported multiple effects on daily life as a result of being on dialysis. The amount of time spent on the treatment was repeatedly mentioned. Several participants were frustrated with having to remain immobile for the four hours or so of dialysis. Along with the hours needed for treatment, participants also reported the time lost in travelling to and from the dialysis centre. In all, this left no time for other activities on dialysis days, especially if they felt unwell after dialysis and had to rest for a while afterwards.

The time commitment to dialysis forced some to give up activities that they enjoyed, including travel, hobbies such as fishing, or part-time work. Relatively inflexible dialysis schedules also meant that participants progressively withdrew from social engagements, thus significantly changing their social roles.

"But I'd spend, and I used to work behind the bar on a voluntary basis one night a week. There was always something to do and I've always got involved in things. And since I've been on dialysis … I had to give it away."

[P14, Male, 78]

Several participants commented on the cyclical nature of symptoms related to dialysis treatments. Significant tiredness was common after dialysis, especially if there had been large fluid removals during the session. This tiredness slowly improved until the next day, when they felt much better, only to reappear the following day after the next dialysis treatment. These repeating cycles of severe fatigue and relative wellness contributed to the intrusive nature of dialysis. It prevented participants from committing to activities outside of dialysis. It also made them increasingly dependent on external help, especially during the days of post-dialysis fatigue.

"...my kids used to say, ~You've got an extra day off. We can go off here, we can go there... but you don't, those days is when you feel like you want to have a bit of a rest or something because, as I said, you feel, you don't feel like you're full of bean."

[P15, Male, 82]

The food and fluid restrictions imposed impacted participants' daily lives and their social interactions. Fluid restriction was difficult for some; participants had to be conscious about these restrictions all the time, particularly when eating outside the home (including when eating with family or friends). Others felt that fluid restriction contributed to symptoms such as constipation and this prompted them to be non-compliant.

"But it's hard, because I've been … with clubs and things like that, and to go and have a drink and a cup of tea and, so now I'm not allowed to have it."

[P1, Male, 74]

A few participants understood the necessity of restricting fluids, and made necessary adjustments, believing that their adherence to fluid restriction enabled them to do well on dialysis. Families and friends also contributed to helping patients maintain their restricted diets.

Most of our participants were retired from work. One of them had his own business but reported that the time commitments of dialysis had forced him to hand over responsibility for everyday matters to others. Those who did not have financial stability reported difficulties with the increased expenses. This was particularly true for those that lived far from the dialysis unit if they had to pay transport charges. Some participants had to move homes to be nearer to the units, once again interfering with social connections.

Dialysis and Others

In this population of dialysis patients over the age of 70, relationships with others - partners, other family members, friends, neighbours and healthcare professionals - were important in how they experienced life on dialysis.

The presence of a loving spouse or family members appeared to influence the decision to start and continue dialysis. As our cohort experienced increasing loss of physical abilities, people around them helped them cope. Many received help with activities in the house. Others were assisted with chores such as tending to the garden or shopping at supermarkets. This support structure of family and friends had positive influences on how they coped with dialysis.

Friends and neighbours were also relevant to most participants, for both the practical benefits in and around the house as well as the psychological benefits of interacting and staying in touch. Some participants considered it important to maintain relationships not connected to their life on dialysis. Other participants mentioned that over time the staff and other patients and families at the dialysis became part of an extended group that they could relate to. Dialysis provided an environment to meet more people. The shared experiences of dialysis, including the many restrictions, the long hours spent together at the unit and the similar interactions with healthcare personnel, strengthened these bonds. The camaraderie and humour lifted spirits.

> *"Yeah, I think so, it helps you with your, you talk about, well some will moan and groan about things, and some will just talk like happy-go-lucky, and just forget their illness, talk about other things…"*
>
> *[P17, Female, 80]*

Our participants all had close relationships with nurses, and acknowledged the central role played by nurses in their lives. For patients on haemodialysis, the nurse looking after them on the day had a significant impact - both on the conduct of dialysis (including needling of the AV fistula) as well as through how they made the participants feel. Both positive and negative interactions were recounted. Nurses that took an interest in their patients and spoke kindly were appreciated. Overall, most participants appeared grateful for the care they received from their nurses and considered them part of a "new family"; there were several anecdotes of humorous interactions.

At the same time, comments were made regarding the perceived lack of interest in their welfare exhibited by some nurses. Similar to the negative interactions with doctors described below, these episodes impacted participants adversely. Nurses often remind

patients of food and fluid restrictions - participants had varied reactions to this. While some appreciated the advice, others were not happy being told what to do. Thus, it appeared that despite their time on dialysis, there were some participants who still did not understand or accept the restrictions required for a life on dialysis.

> *"Yeah, I mean you know they say oh he's not supposed to do this, not supposed to – hang on a minute, I've got to have some, bloody quality of life. I'm not going to just starve myself."*
>
> *[P2, Male, 73]*

Most participants acknowledged the essential role played by doctors and trusted them implicitly to look out for the welfare of their patients. It was important to get along well with doctors. Participants emphasized how valuable it was to them that doctors considered them as individuals and showed respect and involvement. A sense of humour was appreciated. Tone of voice, manner of speaking and consistency of behaviour were important too.

> *"…but just his approach to the patient and everything like that, always ready to listen and smile on his face."*
>
> *[P5, Male, 75]*

Negative interactions with doctors had a significant impact on the participants. Some participants felt let down by doctors who did not interact well, and preferred health professionals that they could better relate to.

> *"…like every six weeks I'm supposed to come, and you talk to the nurse and don't talk to me?…[made me feel] that I was inferior, that he thought he was too good to talk to me, do you know what I mean....but this other doctor has been different."*
>
> *[P6, Female, 75, discussing clinic visits to her specialists]*

Our older participants relied on health care professionals for most of their medical information. Some participants were involved in their own care and were enthusiastic about asking questions to understand their treatment or the working of the dialysis machine. For others, there was no desire to gather more information and instead they relied on professionals "knowing what they are doing".

Interestingly, some participants felt doctors could not help because doctors were too busy, or that they had not experienced first-hand what patients had gone through. This difference was highlighted by a participant who stated:

> *"He [the doctor] hasn't fallen on the floor, he hasn't, and carted him off to hospital so he's okay, you know. So, as far as I'm concerned it is a waste (to speak to doctors)."*
>
> *[P1, Male, 78]*

These beliefs eroded their trust in the doctor-patient interaction; they stated that there was no benefit in meeting their doctors regularly. Such comments were common when they felt that medical professionals had not been attentive enough or had not communicated well enough to satisfy their expectations.

Several participants commented that the experience of dialysis was quite different to what they had expected, or that they had not been given enough information.

> *"They just plonk you on the machine and that's it, you know, they do it, and they didn't explain things."*
>
> *[P16, Female, 75]*

Even participants who had received formal, structured pre-dialysis education regarding dialysis treatment did not retain all of the information received. (We could not explore, within the limitations of our design, if the participants had deficits in learning, memory

or other aspects of cognition, or whether the methods of patient education locally available were unsuitable for this older cohort.)

5.2.5 Discussion and Synthesis

Our findings reflected the intrusive nature of dialysis, which impacted on almost every aspect of the life of the older adult on this treatment. There were four main overlapping meta-themes spread across domains: loss, uncertainty, acceptance and support (Table 5-2).

Table 5-2: Themes arranged according to domains

Domain	Loss	Uncertainty	Acceptance	Support/ Relationships
Dialysis and the self	- Of choice: it is now either dialysis or death - Of control: nothing can be done about it - Of identity; personhood: dialysis must go well for me to be okay - Of pre-dialysis life: role, activities, ideas for the retired life	- Dialysis sessions (determine how I feel) are unpredictable - The machine tells you how I am doing, not me. - Rely on HCPs to communicate clearly: otherwise, I know nothing. - No future hopes, other than to continue dialysis until death.	- Rationalizing the need to be on dialysis - Positive outlook - Taking control of life - Use of humour to cope - Life is worth living, purposeful	- Relationships are crucial: as support and as reason for living - HCP interactions are crucial - HCPs cannot do much if they do not know how I live
Dialysis and the body	- Of the sense of "normality": now the machine-led life. - Of wellbeing: the prominent	- About needling of AV fistula - pain, bleeding - Unpredictable symptoms caused by dialysis	- Acknowledge effects of ageing - Ask for help when needed - Symptoms relieved by dialysis	- Receiving help to look after oneself - Discussion of advance care plans with family, HCPs - Discussing health issues with HCPs

Domain	Loss	Uncertainty	Acceptance	Support/ Relationships
	symptoms during and after dialysis - Of health: other medical issues continue - Of physical and mental functions through ageing.	- Fluid removal on dialysis and its effects: on energy, on BP - Discomfort in the dialysis unit- chairs, temperature - Other persistent symptoms - Other unexpected illnesses - Thoughts about mortality	- Pragmatic discussions about death and functional limitations - Participation in advance care planning, including options for dialysis withdrawal	
Dialysis and daily life	- Of time: for everyday things; social activities - Of dietary choices: fluid and food restrictions - Of travel possibilities: all trips linked to dialysis services - Of finances: transport costs, phone bills, lost earnings	- Repeating cycle of wellness and fatigue around the days of dialysis - Episodic nature of haemodialysis: the need to arrange life around dialysis times - What is done on a day depends on how the dialysis session went.	- Choosing activities according to situation & capability - Optimising health to engage in preferred activities - Seeking help where needed - Accepting and modifying diet/intake	- Receiving support from HCPs/ allied health - Maintaining and strengthening helpful relationships among family and friends - Making time for social activities

Domain	Loss	Uncertainty	Acceptance	Support/ Relationships
Dialysis and others	- Of social ties - Of agency: the new need to comply with HCP instructions, rules for dialysis patients	- Others did not communicate: dialysis is not how I expected - Social commitments now depend on dialysis schedules	- Accepting help where available - Choosing to adhere to HCP recommendations	- Engagement with HCPs to improve the experience of dialysis - Maintain activities / relationships outside dialysis - Family / friends / relationships that are nurturing - Dialysis unit as a new family or social outlet

Loss

Our population of older patients on dialysis felt a pervasive sense of loss across all the four domains of experience. Lindquist speaks of the dialysis patient's wishes for independence and normality - both these subjective feelings are lost when on dialysis (226). Participants reported significant changes to their lives after starting dialysis, similar to the feeling of "life being lost" described by Monaro and colleagues (227). Changes in participants' concepts of themselves were seen when they described their health in terms of machine performance or biochemical targets. Various authors have described this as a transition into a life restricted (228); not finding space for "living" (229) or a life with physical shackles (230).

McDonald described a continuum in responses to a life on dialysis, one aspect of which is a struggle between control and acquiescence (231). Similar to this, in our population, some participants felt disempowered by their losses, while others learnt to adapt to

them and carry on. Such participants described positive adaptation and the transformation to a new self, capable of dealing with the new realities, and appeared to have good outcomes on dialysis (see discussion below).

Uncertainty

Uncertainty is another concept that spans several domains in our results. The repeated cycles of tiredness and improvement coinciding with haemodialysis sessions three times a week meant our participants were never sure of how they would feel, since dialysis sessions determined their status (variables such as large fluid removal targets, problematic needle insertion into the arteriovenous fistula or the behaviour of the dialysis nurses or doctors on the day). These feelings of vulnerability and uncertainty have been highlighted in several similar studies in the literature (229,232).

The future was unclear; several participants acknowledged that longevity was not certain and were happy to discuss advance health care directives. The inadequacies appearing with ageing and the experience of other dialysis patients (or other older acquaintances) dying impacted on their own outlook for the future. This uncertainty introduced by dialysis could worsen the tendency of older adults to have lower "meaning in life" scores (233).

Acceptance / adaptation

Several researchers have studied the process of ageing, prominent in the narrative of our participants, as a process of adaptation to declining physical and cognitive capabilities (234,235). Previous studies have identified the theme of "attempting to maintain manageability" as part of life on dialysis (229). We identified adaptations in our older population as a series of changes - in lifestyle, activities, diet, fluid intake and mental attitude, undertaken with the aim of optimizing outcomes. In general, patients who tended to do well adapted to dialysis in positive ways, seeking to optimize their

lives and in this way, to maximize the benefits of the restricted life on dialysis. Rittman describes this attempt by patients on dialysis to retain control over their lives by negotiating a new understanding of life and maintaining hope (236). This contrasted with those reports where patients did not show this acceptance, and instead focused on the difficulties. These patients did not engage in making adaptations to life in order to deal with adversity (237,238).

Relationships and support

Family members (and/or friends) had significant impacts on how life was perceived. Some participants felt that the involvement of their family was responsible for their positive experience of dialysis; on the other hand, others stated that they stayed on dialysis in order to take care of their family members. Interactions with family - including the new acquaintances at the dialysis unit - were related to "meaning in life" and to hope for the future. This is consistent with other studies which describe the ageing patient attempting to regain control of their life roles as their care situation or dependency needs change (239).

Nurses played an important role in the lives of these patients. Their skills and their interactions with patients determined how dialysis was perceived. Similar observations have been reported by Madar, who commented that nurses have significant impacts on reducing the stress of dialysis (240).

With regard to the relationship with doctors, the need to be seen as “normal” "as a human being", and "with respect” was manifest, similar to other qualitative studies (229,239). There was a spectrum of variable expectations from older patients on dialysis, emphasizing the importance of an individualized approach based on patients' needs.

Table 5-3: Predictors of a good outcome and methods of assessment, derived from reflexive interpretative analysis

Physical factors:

- prominent uraemic symptoms that may be relieved by dialysis (e.g., nausea, anorexia)
- low levels of pre-existing frailty/physical dependence
- absence of pre-existing significant symptoms that are unlikely to be relieved by dialysis (e.g., chronic pain, depression)
- the ability to tolerate dialysis, particularly fluid removal
- a functional access for dialysis which is not problematic to use/maintain

Psychological factors:

- lack of conflict or ambiguity around the decision to start dialysis
- expectations from dialysis that are reasonable and achievable
- illness perception - an internal locus of control, willingness to take responsibility for own health
- understanding of dialysis treatment and need for lifestyle changes, food/fluid restrictions
- actively choosing a positive attitude; not "giving up", willingness and opportunity to adapt to changing circumstances
- hopeful; engaged with the future; "meaning and purpose" in life

Social factors:

- family as motivation: providing physical/psychological support, family that requests continuance on dialysis or other treatment, participants who continue dialysis in order to be able to look after their family members
- involvement of close family/friends/carers in daily life, in healthcare decisions
- participants who derive social benefit from interactions of the dialysis unit (particularly if socially isolated)
- ability to travel or engage in other activities (personal or social) separate from dialysis

Healthcare provider/institutional/societal factors:

- positive relationships with healthcare providers, where patients feel valued and listened to

- appropriate skill sets among medical and nursing staff
- opportunity to consider or participate in advance care planning
- patient-friendly staff and dialysis facilities (e.g., flexible schedules, comfortable chairs, adequate heating)
- easy access to dialysis facilities, including proximity, transport arrangements
- financial stability or lack of financial penalties from being on dialysis
- access to social/formal community support that is affordable and always available

5.2.6 Conclusions: Our results in the context of clinical practice

The predictors of a good outcome on dialysis, listed in Table 5-3, were postulated by reflexive analysis, drawing interpretations from participants' descriptions of positive and negative experiences on dialysis. Most of these factors can be assessed using targeted history-taking, or using several validated questionnaires and other tools, some of which are listed in Table 5- 4. When indicated, some psychological factors may be amenable to interventions such as cognitive behavioural therapy. Our research also highlights several social factors which have an influence on dialysis outcomes, thus highlighting the importance of a holistic approach to the elderly person considering dialysis.

Table 5-4 offers some practical suggestions to mitigate poor outcomes on dialysis for the elderly and provides a list of objective assessment tools that may be useful. Nephrology teams may not possess all the skills required to ensure good dialysis outcomes for the elderly, and a multidisciplinary approach, with involvement of other specialists,

including geriatricians, psychologists, nurse educators and social workers may be optimal.

The importance of providing complete and detailed information cannot be overstated. More than mere altruistic intent, such an approach contributes to optimal conduct of shared decision-making and has legal relevance in the domain of informed consent for dialysis (241). Providing comprehensive information, and ensuring this information has been understood is one of the basic elements of a legally valid informed consent (241).

Table 5-4: Some interventions to improve dialysis outcomes

Factors potentially leading to poor outcomes	**Suggested Interventions**	**Objective Assessment (clinical / research purposes)**
The decision to have dialysis framed as a choice as between dialysis (living) versus dying; decisional conflict	Specific discussions around choice; presentation of alternatives to dialysis such as maximal supportive care; involvement of family / carers in decision-making	Decision support aids (e.g., web-based aids, (242) The Canadian CKM Care decision aid(93,243) The Yorkshire Dialysis Decision Aid (YODDA) (244)) The 'SURE' test (245)
Undue expectations of symptom benefit from dialysis	Discuss inconsistency of symptom relief; appearance of new symptoms with dialysis (e.g., needling pain, fatigue)	Symptoms /quality of life surveys (210) Frailty indices (246) Comprehensive Geriatric Assessments (CGA) (247) Assessment of health literacy (248) Becker-Maiman model for analysis of compliance (249) Beliefs and Behaviour Questionnaire (BBQ) (250) Dialysis Diet and Fluid non-adherence Questionnaire (251);
Being ill-prepared for the restrictions and the reality of life on dialysis	Information tailored for the older patient (more time, more repetition); Specifically discuss restrictions to travel, diet, fluid intake	
Effects of ageing, physical or cognitive decline	Screen for frailty and risk of falls; prevent deterioration if possible, address frailty, monitor functional status, provide support before the patient "fails"	

		Illness perception questionnaire(252)
Curtailment of activities outside dialysis; changing life-role	Explore personal values, discuss impacts of dialysis on the rest of the patient's life	
The time commitment; losing time for 'living'	Specifically discuss time lost - including time needed for travel, and the time lost resting after dialysis.	
Impact and recurring nature of post-dialysis fatigue	Warn patients of cyclic nature of symptoms like post-dialysis tiredness and their impact on life	Dedicated fatigue scales / inventory (253)
Lack of a "positive attitude", actively adapting to effects of dialysis on life	Clinician focus and involvement in facilitating psychological adaptation, consider behavioural therapy if needed	Illness perception questionnaire (252) Inventory of Coping Strategies Used by the Elderly ICSUE(254) Life Attitudes Profile (255) Personal Meaning Profile (256)
Inability to maintain or enjoy goals /values / activities outside of dialysis	Encourage and plan with patients regarding: Selecting the right activities according to current limitations, optimising self for their performance, and making compensations / accepting help where needed	
Loss of the feelings of being valued, loved, supported.	Focus on meaningful clinician interactions; monitor support from family, friends; Consider needs of carers.	Quality of life scales (210) Trust in Physician Scale (257) Zarit Burden Interview (258)

The realities of ageing and its associated problems continue for patients on dialysis, as do the difficulties caused by other comorbid conditions. Patients reporting good

outcomes have often modified their activities according to capability, accepted support from those around them, and sustained beneficial social ties. An active choice to undertake dialysis treatment, with awareness of the difficulties of life on dialysis and in an environment of adequate support will increase the chances of being able to adapt successfully and experience good outcomes.

5.3 The influence of illness perception and personality on outcome

5.3.1 Background

The study of illness perception in patients begins with the premise that there are rational appraisal processes that come into play when faced with illness and its symptoms. The patient forms a perception of illness based on these symptoms and their cognitive and emotional effects. This perception then activates certain health-related behaviours in order to restore well-being. These assumptions form the basis of Leventhal's Self-Regulatory Model (SRM), which posits that patients form a "common-sense understanding" of illness based on their perceptions, and these perceptions drive self-regulatory behaviour that attempts to restore normalcy (259). This model suggests five components of illness perception, namely - identity, cause, time-line, consequences and cure or control. These components can be tested for using the Illness Perception Questionnaire - Revised (IPQ-R) survey, which has been validated in patients with ESKD (260,261). Illness perception attributes have been correlated with quality of life and mortality in patients with ESKD (262–266).

Similar to illness perception, there is evidence that a patient's personality can influence their outcomes on dialysis - in terms of survival, quality of life or coping methods (267–270). In order to test if personality type or characteristics influenced outcomes, we administered the "Big-Five Personality Test" to our participants. This test scores participants on the characteristics of the major personality types, namely extroversion, agreeableness, conscientiousness, openness and neuroticism (271,272).

The following analysis, which considered the influence of illness perception and personality type on the outcomes with dialysis, was performed concurrently with the study described in 5.2 above, but was not included in the research report sent for publication as this was outside the scope of the targeted journal. This ancillary information is presented here.

5.3.2 Aims and objectives of additional analysis

1. To test for a correlation between the components of illness perception (identity, cause, timeline, consequences and cure or control) and markers of quality of life outcomes on dialysis (physical and mental component scores, and answers to the "overall health rating" question on the Kidney Disease quality of life Short Form v 1.3 survey); and

To look for correlations between personality type characteristics (extroversion, agreeableness, conscientiousness, openness and neuroticism) and markers of quality of life outcomes on dialysis (physical and mental component scores [PCS and MCS respectively], and answers to the "overall health rating" question on the Kidney Disease Quality of Life Short Form v 1.3 survey).

5.3.3 Methods

Selection of patients, inclusion and exclusion criteria have been detailed in the report for publication presented in 5.2.1.

In order to study illness perception, we administered the IPQ-R survey, which generated numerical scores for each of the components of illness perception detailed above. In order to study personality characteristics, we used the 'Big 5 Personality Inventory', which generated numerical scores for the participants on the five

personality traits detailed earlier. Both surveys were administered prior to the patient interviews.

In order to document quality of life outcomes, we performed a cross-sectional survey of the participants, using the KDQOL-SF v 1.3 quality of life survey (please see Chapter 3 for details of this survey tool). For outcome variables, we used summary scores of physical and mental aspects of quality of life obtained from this survey (the Physical and Mental component scores), and the answer to a single survey question about overall heath ("How would you rate your overall health?"). We then looked for correlations using Spearman's rho, with a p value of <.05 considered significant.

5.3.4 Results of additional analysis

The distribution of personality traits in dialysis elders was unremarkable, as shown below:

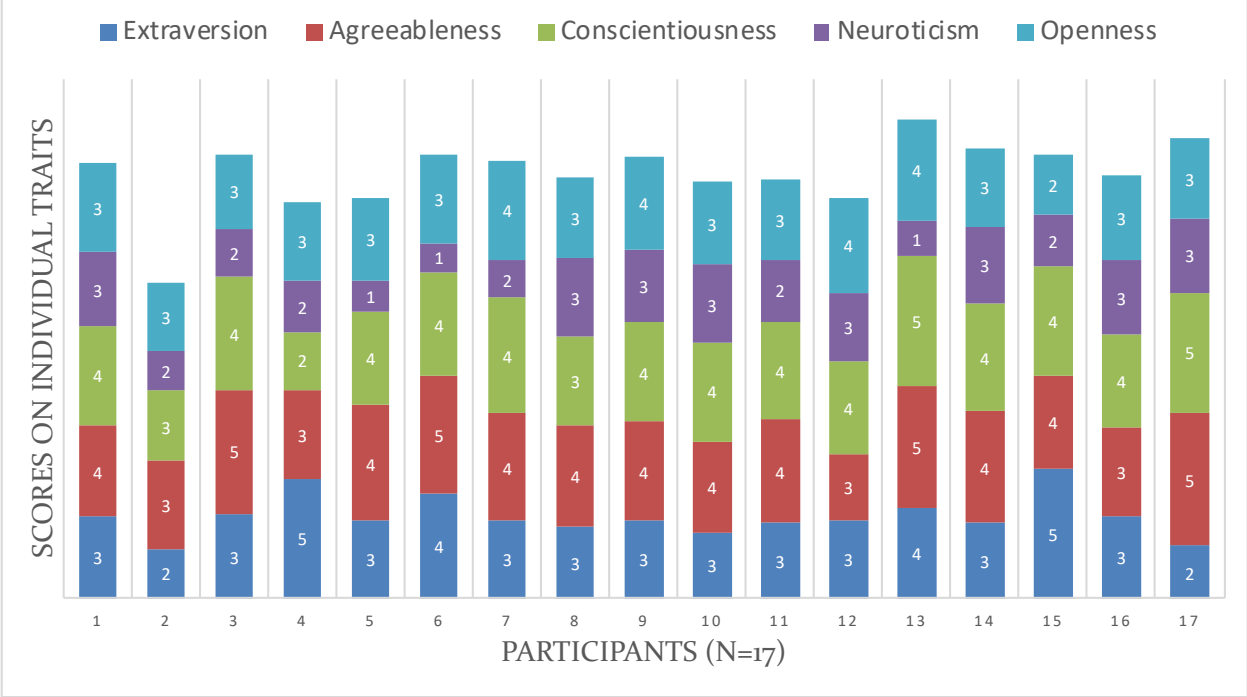

Figure 5-8: Distribution of personality traits in study participants

We compared scores on the components of illness perception in our cohort with their quality of life scores and their assessment of overall health, testing for correlation using Spearman's rho. Among personality traits, significant (p<.05) correlation was seen between extraversion and the rating of overall health (ρ = .55), neuroticism and rating of overall health (ρ = -0.6), neuroticism and MCS (ρ= -0.6). Among illness perception characteristics, the concept of time (i.e., chronicity) was correlated with PCS (ρ = .61). No other correlation was found between personality traits, illness perception and these markers of outcome.

The influence of personality traits on the responses to chronic illness is an intriguing area of research, especially in long-standing, potentially incurable diseases such as multiple sclerosis. It can be postulated that an extroverted personality is better able to cope with the rigours of dialysis treatment and may actually thrive in the open, communal nature of the dialysis unit. Similarly, it is conceivable that neuroticism, a measure of distress and anxiety, is correlated with a negative rating of overall health and a negative mental component score of health-related quality of life. Despite our very small numbers, these results are worthy of interest. The influence of personality on outcomes in chronic kidney disease has been previously reported in a Malaysian population (273). Similarly, illness perceptions have been known to affect survival and quality of life in patients with renal disease (274,275). It is conceivable that therapeutic targeting of these illness perceptions could improve psychosocial outcomes (276). These areas need further research.

5.3.5 Conclusion

Personality traits and illness perception concepts appeared evenly distributed in this small population. Within this group, we found small correlations between personality traits and outcomes of quality of life, but acknowledge that larger numbers would have

yielded more accurate results. However, our primary objective was the qualitative analysis of the interviews, and data collection was stopped after 17 participants, once saturation of themes was noticed. A separate future study, adequately powered, may provide different results.

Chapter 6:
Discussion and Conclusion

6.1 Overview

> *Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short, not often painful illness, the old man escapes those 'cold gradations of decay' so distressing to himself and to his friends.*
>
> – Sir William Osler, writing in 1912 (277)

When older persons choose treatments that could extend their lives, a worthwhile consideration is that of the quality of the life so gained - it is still important to avoid the 'cold degradations of decay' quoted by the prescient Sir William Osler more than a century ago (although pneumonia may no longer cause the mortality it once did in the pre-antibiotic era). Life expectancy is increasing, and medical progress has ensured that life-sustaining treatments for previously fatal illnesses like end-stage kidney disease are now widely available (278). Dialysis is a typical example for a life-sustaining treatment now widely available to the elderly. But while it extends life, it can completely alter lives for the worse in some older people and cause a significant decline in quality of life. Clinicians discussing dialysis treatment with older people are frequently asked for advice to address this dilemma that older patients and their families have to grapple with.

Through the research projects in this thesis, I set out to explore aspects relevant to the treatment for end-stage kidney failure in older patients. Three areas of study were

chosen – an analysis of the available literature on the information that clinicians could use in discussions about treatment choice, the quality of life outcomes on dialysis as influenced by physical symptoms and an exploration of older patients' perspectives of outcomes from dialysis. Finally, from an interpretative analysis of these research findings, I aimed to develop a comprehensive checklist that could be used by clinicians counselling older patients with ESKD, such that all important factors (identified from the literature review and from my own research) could be addressed. In the course of this work, I was additionally able to generate a list of initiatives that clinical teams could take to improve the lives of older people already on treatment.

The following sections describe how I addressed each of these objectives through the studies carried out. Subsequently, I discuss in this chapter the contributions to the literature from my research. Finally, I reflect on the potential impact of my work on the field and consider the future.

6.2 Research outputs mapped to objectives of research projects

6.2.1 Scoping review: information for older patients considering dialysis

As discussed earlier, in the scoping review of literature from 2000 to August 2018, I attempted to collate the information relevant to the discussion of dialysis options with older patients.

Survival on treatment is an important concern for clinicians and patients. By referring to annual statistics published by data registries in a particular region, an overall estimate of the usual survival rates on dialysis for particular age groups may be obtained (279).

However, patients often ask for more individualised prognosis. Within the literature, prognosis was linked to sociodemographic factors such as age, aspects of nephrology care and dialysis treatment, other co-existent illnesses, functional status, nutrition, body composition and individual biochemical tests. Some of these factors have also been combined into indices that could be used in the elderly population to predict survival with various treatment options. Additionally, I highlighted indices that predicted the risk of developing renal failure (and therefore the risk of eventually needing dialysis). To guide the appropriate use of the indices, I highlighted the populations in which the indices were derived, the cohorts used for validation and statistical information about the discriminatory abilities of the indices. From the available information, as summarised in Chapter 2 (p 71), the Kidney Failure Risk Equation derived by Tangri et al may be used for calculating the risk of end-stage renal failure developing in a given patient; and the Bansal index may be used to estimate the risk of mortality, to sub-select a group at high risk of mortality, who may be suited better to a non-dialysis, conservative pathway (84,118,184).

I also provided a comparison between the survival with dialysis versus that with non-dialysis, conservative care. This is relevant particularly to the older patient with multiple other co-existent illnesses, in whom the benefits of dialysis treatment are less certain. Table 6.1 is derived from the information previously presented in table 2 . 4 regarding the comparison of survival between dialysis treatment and conservative care.

Table 6-1: Survival differences between CM and RRT summarised by age groups

Population	Survival: CM versus RRT (months)	Specific sub-groups	Comments
Age > 80			
Age> 80; recommendation for CM by clinical team			
Cr Cl < 10 (134); single French unit	8.9 vs 28.9		Late referral, poor nutritional and functional status in CM group; peripheral vascular disease affects mortality at >1 yr
Age > 80; choice of CM by patient			
eGFR <20, (16); single UK unit	Survival less with CM	Those > 80 – no survival advantage to RRT	
eGFR < 20 (140); single Dutch hospital	17 vs 25 (n.s)	Those > 80 - no survival advantage to RRT	
eGFR < 15 (141); single Spanish hospital	No difference	Those > 80 - no survival advantage to RRT	
Age > 75			
eGFR ≤ 15 (74); 4 UK units	18 vs 19.6 (n.s)	Those with severe comorbidity: no significant survival difference	1- and 2-year survival better overall with RRT, except with comorbidities, IHD in particular
eGFR 10 -15 (136); single UK clinic	29.4 vs 36.8 with low comorbidity; 20.4 Vs.25.8 (n.s.) with high comorbidity	Those with severe comorbidity: no significant survival difference	
eGFR 16 (139); single Australian unit	19 vs 31	Those with severe comorbidity: no significant survival difference	Cardiac comorbidities are significant
eGFR 10 -15 (142); single UK clinic	23.1 vs 38.2 overall 20.3 vs 28.4 with high comorbidity	Those with high comorbidity, only marginal advantage of RRT	Rapid rates of eGFR decline worsens survival in those > 75 managed with CM
Age > 70			
eGFR 10.8 (135); single UK clinic	13.9 vs 37.8		Similar number of hospital-free days in both groups

eGFR <20, (16); single UK unit	Longer survival with RRT	Worsening performance score or increasing comorbidity reduced the advantage	Across all 3 groups – eGFR<20, <15 and <10
eGFR < 20 (140); single Dutch hospital	At eGFR <15: 18 vs 37 At eGFR<10: 6 vs 34 High comorbidity: 12 vs 21	Increasing comorbidity reduced the advantage	
eGFR < 15 (141); single Spanish hospital	Overall: 39 vs 65 After eGFR<15 21 vs 46		
Age > 65			
eGFR≤ 15 (138); single Hong Kong center	28 vs 45		CM compared to PD alone Hospitalisation risk lower with PD
eGFR <10 (143); CM at single Austrian centre compared to registry RRT data	1.1 vs 26.9	With comorbidities, survival benefit for RRT did not persist beyond 2.9 months (females) or 1.9 months (males) compared to CM	

It is difficult to arrive at composite scores of survival because of significant differences in the patient groups studied and the methods of estimation of comorbidities. However, a few generalisations can be made. In those over 80, multiple single-centre studies have shown no benefits of dialysis over conservative management. In those over 75, the presence of comorbidities significantly reduces or even negates the survival advantage of dialysis over conservative management. In those over 70 years old, as well as those over 65, single-centre studies show a survival advantage of dialysis that appears to decrease as patients have increasing comorbidities. From these studies, the need for multi-centre studies with standardised definitions of conservative management and

standardised descriptions of comorbidities is obvious. Additionally, it can be seen how survival alone is not a very good factor to consider - especially in those situations where the difference between the two treatment pathways is marginal. A focus on mere survival also takes the discussion away from the very real changes in lifestyle and overall quality of life that dialysis treatment brings about: a consideration that may be particularly important to certain patients.

The next objective of the scoping review was to identify factors influencing quality of life on treatment. I identified potentially modifiable factors, such as functional or nutritional status, symptom burden or depression, as well as some non-modifiable factors like age or gender. Together, these factors allow clinicians to discuss potential effects on quality of life when talking to those considering dialysis.

As anticipated, the study of descriptions within the literature of the lived experiences of older people was relevant to the discussions with prospective patients – these reports mentioned the importance not only of physical symptoms but also that of psychological factors when on treatment. Patients wanted more information and involvement. Positive relationships with family members and with clinicians were valuable.

I also explored what patients want to hear from clinicians during these discussions by including research on information needs of patients and their families. I reported that while patients desired information about their disease, its treatment and prognosis, they also had other considerations that relate to individual factors, the needs of family and friends and to the demands on time.

6.2.2 Outcomes on dialysis: Quality of life - studies of symptoms, their recognition and influence on quality of life

Two studies addressed the topic of symptoms in ESKD patients. First, we studied symptom burden in dialysis patients and confirmed that patients with end-stage kidney disease, including those on dialysis or those undergoing conservative, non-dialysis care, suffered a significant burden of symptoms. This study was also able to show correlations between increased symptoms and lower quality of life. A high burden of symptoms is a factor that could lead to a lower quality of life – a finding that was reflected in our own patient sample.

The second component of this study was investigating how well these symptoms were identified by healthcare professionals. We were able to show that there was poor recognition of symptoms by nurses and doctors looking after dialysis patients. This inattention to symptoms is a potentially modifiable factor affecting outcomes on dialysis.

A possible solution to this poor recognition of symptoms in routine clinical practice could be the introduction of patient-completed symptom surveys. The IPOS-Renal Symptom Survey is a commonly used tool in Australia, even though it has not previously undergone validation among the dialysis population. As part of this PhD research, we performed, to our knowledge, the world first validation of this survey in a dialysis population. We demonstrated the reliability and validity of this instrument in a cross-sectional study of dialysis patients. We can now suggest that this symptom survey can be reliably used in clinical practice and research to document symptoms in the dialysis population.

The outcomes of this research have been translated into clinical practice – patients within our renal units now regularly complete the IPOS-renal symptoms survey as part

of routine clinical practice. It remains to be seen whether the enhanced detection of symptoms leads to better treatments and reduction of symptom burden. This is a potential area for future research. I am now an investigator on an international clinical trial, the Symptom monitoring WIth Feedback Trial (SWIFT), which is a registry-based cluster randomised trial, funded by NHMRC and Kidney Health Australia, coordinated through the NHMRC clinical trials centre, University of Sydney and the South Australian Health and Medical Research Institute. The trial is designed to investigate whether symptom monitoring with the IPOS-Renal survey, followed by feedback to treating clinicians, and the provision of evidence-based guidelines for symptom management, will eventually impact quality of life and mortality. The trial protocol has been registered with the Australia- New Zealand Clinical Trials Registry (registration number ACTRN12618001976279; details available online at https://anzctr.org.au) (280).

6.2.3 Outcomes on dialysis: The perspective of the elderly patient

Our qualitative interviews to explore the experiences of elderly patients provided us a unique perspective to describe dialysis outcomes from the point of view of the older dialysis patient. While there were frequent considerations of ageing and mortality, older patients' experience of the outcomes of dialysis were characterised by a pervasive sense of loss of various aspects of their pre-dialysis existence, coupled with a recurring sense of uncertainty about their day-to-day lives and the future. Patients identified the successful acceptance of the difficulties caused by dialysis and the availability of support from their clinicians and family/friends as key to improving their outcomes. When clinicians are sensitive to these concerns, there is potential for improvement of outcomes in the elderly – this is discussed in the next section.

6.3 Actionable outcomes from research

In the following sections, the insights obtained from the literature review and the research studies have been used to suggest (i) checklists for the shared decision-making process around choosing treatment options, and (ii) potential initiatives for improving the experience of patients already on treatment. These lists are intended for clinicians caring for older patients with end-stage kidney disease.

6.3.1 Checklist for discussions with patients considering dialysis

Discussions with older people considering dialysis are conducted in different settings. For most patients, renal impairment is slowly progressive, and there are usually several opportunities to discuss the pros and cons of the various treatment pathways. However, the patient who presents in extremis, needing urgent, life-saving treatment for kidney failure often ends up starting dialysis without an opportunity to have detailed discussions.

The following checklist is suggested to be used during discussions with older people considering dialysis and their families. It combines the information obtained from the literature review as well as from the research conducted for this PhD. It lists potential items for discussion, suggests how they can be considered and provides comment on the practical value of each item. Discussions about treatment options are usually held over many sessions with input from different members on the team, including doctors, CKD educators and nurses, and/or social workers. Elements of the checklist can therefore be operationalised by any member of the clinical team.

Table 6-2: A practical checklist for the shared decision-making process

	Elements of the checklist	Tools	Comment
1	Risk of renal failure	Scores to predict progression [e.g., Tangri, 2011 (24), Schroeder 2017(37)]	Risk of progression determines immediate priorities for counselling and planning
2	Risk of mortality	Scores to predict mortality [e.g., Bansal, 2005(32), Wick 2017 (36),Couchoud 2009 (38)]	Mortality risk can influence choice of treatment. Such information is valuable to patients for future planning and advance care directives. Helps to set realistic expectations from treatment.
3	Comparison between dialysis and CKM	Focused discussion required.	Influences choice of treatment. Helps to set realistic expectations.
4	Expectations from treatment	Focused discussion required.	Reduces decisional conflict and regret
5	Negative aspects of treatment options (including time commitment; new symptoms)	Focused discussion required.	Helps to set realistic expectations; helps reduce regret and encourages adaptation by making patients better prepared
6	Revisit information periodically	Repeated discussion needed	Older patients have trouble understanding and remembering; they often also have cognitive impairment.
7	Probe for decisional conflict	Focused discussion required. Validated tools exist. [e.g., Legare 2010(230)]	Older patients learn differently; make their decisions with input from various others; are likely to change their minds; are likely to have competing interests around all major decisions; there exists a sense of "dialysis or death"; or that not having dialysis is "giving up". Addressing decisional conflict also strengthens the validity of informed consent to dialysis or otherwise.
8	Identify important carers, discuss	Focused discussion required.	Carers are an important source of support for older patients. Patients can undergo physical and cognitive worsening, increasing dependence on carers.

9	Investigate, document and monitor symptom burden	Patient-reported symptom surveys such as the validated IPOS-Renal [Raj, 2018, Davison, 2006(192,213)]	Symptoms have a central role in the experience of treatment; influence expectations from treatment and affect patient-reported outcomes such as HRQOL.
10	Document comprehensive baseline status	Scores such as the Clinical Frailty scale, geriatric nutritional index, cognitive scores (e.g., MoCA), Beck depression index and, Comprehensive geriatric assessments (247,281–283) (233), [See review by Kallenberg 2016 (284)]	Identifies a subgroup at risk for adverse outcomes; enables targeted preventative management and support. Nutritional index screening may require dietician support; other indices can be administered by renal personnel.

While conducting these discussions, it is worthwhile remembering that several elders may have cognitive deficits (or hearing impediments) that interfere with understanding. For checklists such as these to be effective, frequent discussions, with adequate repetition and opportunity for clarification are essential. Future research will focus on measuring the effectiveness of this checklists in leading to outcomes that are optimal and appropriately matched to patients' expectations. Paying attention to the items on the checklist ought to identify those areas of the patient journey most salient for that individual patient. Finally, one must consider that these vulnerable older patients often have other illnesses too, and therefore there are many other, holistic and age-related considerations to planning long-term treatment. Specialist geriatric intervention - whether through hospital-based geriatricians, nurses or community-based support services, are an integral part of care for the elderly with chronic illness.

6.3.2 Potential initiatives by clinical teams to improve the experience of treatment for older people

1. Provide appropriate information.

Our qualitative research findings and reports from the literature collectively suggest that older patients on dialysis often report inadequate provision of information. There are potentially several reasons for this, but an easily modifiable factor would be to ensure that information routinely provided and is tailored to the older adult. Clinicians should receive training/upskilling in communication skills. Some educational initiatives to improve communication skills (e.g., "Nephrotalk") exist, these are likely to make a difference (285,286). Older adults will require more time and repetition of information before they gain sufficient understanding. When providing such information, it will be useful to address the issues most relevant in this population such as the limited prognosis, the inconstancy of symptom relief, the appearance of new symptoms with dialysis and the lifestyle changes required to continue dialysis, especially in-centre haemodialysis.

2. Introduce patient- reported symptom surveys, such as the validated IPOS-Renal survey.

This enables the enquiry and capture of common symptoms, the grading of their severity and monitoring their response to treatment measures. As discussed earlier, there are potential benefits to improving symptom recognition.

3. Focus on individual patient needs, with sensitivity to patients' perceived sense of loss.

Healthcare professionals ought to consider, in partnership with their patients and carers, the things most important to patients and discuss how they are (or may be) affected by undertaking dialysis or conservative management pathways. This is

relevant because older patients often face several 'losses' of their previous life-roles as they adapt to life on dialysis, with a significant impact on how patients perceive their outcome on dialysis. This could help prevent regret and enable a healthy adaptation to a life on dialysis.

4. Be attentive.

Patients also expect appropriate attention from their physicians and nurses. Attributes of interactions considered valuable by patients include treatment with dignity, humour, encouragement of patient participation and the perception that the patient is being treated "as a person". Clinicians play a crucial role in these patients' lives, and the support provided by clinicians is vital to achieving good outcomes.

5. Adopt a proactive approach to addressing causes of uncertainty for patients.

Particularly for patients on haemodialysis units, there is significant uncertainty around the outcomes of each dialysis session (for instance, the pain from needling of arteriovenous fistulae or the ill- effects of fluid removal). Dialysis units can improve outcomes by ensuring appropriate technical skills of dialysis nurses and technicians and seeking patient feedback. Adverse effects of dialysis, particularly post-dialysis fatigue, should also be monitored closely. Clinicians should be agile in adjusting dialysis prescriptions, particularly fluid removal.

6. Ensure a comfortable environment for dialysis.

Patients spend several hours on dialysis. Within dialysis facilities, efforts must be made to ensure the physical comfort of patients. Uncomfortable chairs and poor heating were common complaints in our dialysis population. Such concerns with the dialysis environment will obviously be different from place to place, but this is an area that

requires attention since it has an immediate effect on how patients perceive their experience of dialysis.

7. Be mindful of the relationships that long-term patients develop.

Repeated visits to the dialysis units allow patients to develop relationships with nurses, other patients and their carers/families. These ties are important not only as a source of social enjoyment but also as a source of information and shared understanding. Similarly, older adults reported grief following the death of other patients well-known to them. Clinicians and unit administrators ought to acknowledge these close ties between patients, foster these relationships where possible and provide support and counselling to address grief when patients die.

8. Pay attention to management of carers' needs.

Support from the people around the patient makes an important contribution to a good outcome on dialysis. Progressive physical and cognitive deterioration are common in older age groups, forcing patients to assume sick-roles and become progressively more dependent on their careers, family or friends. Management of the patients' needs can only be complete if sufficient attention is paid to the carers who share their burden. Their support and information needs ought to be considered, and where appropriate, carers ought to be involved in the planning and discussions of treatment.

6.4 Contributions to scientific knowledge

The scoping review is the first such review of the information specifically applicable to the older patient with ESKD. This review is a useful summary of the literature between 2000 - 2018. For healthcare professionals counselling older patients, I believe this will be a useful resource, summarising a large body of information within one paper. The

review also contains up-to-date collections of validated prognostic indices and comparisons between conservative management and renal replacement therapy.

We showed a significant symptom burden in Australian patients with ESKD - both for those on dialysis and those on conservative management. We demonstrated that symptom burden among dialysis patients correlated with quality of life scores.

We demonstrated that during routine clinical care, doctors and nurses fail to identify the symptom burden in dialysis patients accurately when compared to patient-completed symptom surveys. Studies such as this also set the stage for future research looking into whether patient-led reporting of symptoms followed by targeted interventions will eventually lead to reduced symptom burden.

We demonstrated satisfactory reliability and validity of the IPOS-Renal symptom survey. The IPOS-Renal is commonly used but was not previously validated for use in this population. Our validation study paves the way for the greater use of this symptom survey in clinical practice and research.

Our qualitative research project contributed a unique insight into older patients' perceptions of outcomes on dialysis. We highlighted the experiences of loss (across multiple domains) and the pervasive uncertainty affecting patients' thoughts about their lives. We also reported on how patients' acceptance of their illness and adaptation to the demands of life on dialysis, coupled with support from carers, nurses and doctors were considered to have positive effects on outcome.

We created a checklist to help the conversations in the shared decision-making process by combining information from the literature and from our own research projects.

We also suggested a list of clinician initiatives to improve outcomes for older patients already on treatment.

6.5 The future: Potential developments and research opportunities

As medical technology advances, it is possible that dialysis therapies can improve as well. A method of replacing renal function that does not have the intrusive nature of present-day dialysis and does not worsen cardiovascular risk may significantly change the discussion around outcomes. Better methods of providing home-based dialysis, with minimal disruption of everyday life, could potentially reduce or abolish the burden of treatment. On the other hand, developments in transplantation could make it a widely available option for the older patient, relegating dialysis to the role of a temporary treatment or a "bridge" to transplantation.

Newer fields of biomedical research – such as metabolomics or proteomics – have the potential to help us understand the causes of disabling symptoms, give us new methods of prognostication using novel biomarkers or even suggest targeted, individualised treatment for the new mechanisms of illness they could uncover. Advances in analytic technology, computing power and artificial intelligence have the potential to dramatically increase the amount of information we have about our patients – such innovations could have a significant influence and change the existing paradigms of care.

As we wait for these developments however, we must continue efforts to improve outcomes for ESKD patients. Targeted management of patient reported symptoms might be an easily achievable method of improving quality of life; however, more research is needed. Specifically, interventions based on regular reviewing of patient-reported outcome measures need to be shown to be effective in improving health-

related quality of life. As discussed above, the outcomes of the proposed SWIFT trial will be particularly relevant to this area of research.

Similarly, it remains to be seen if detailed discussions, repeated often, providing information tailored to individual preferences and expectations will improve satisfaction with treatment and, by association, treatment outcomes. The influence of illness perception and personality type in the older patient also warrants further exploration. Interventions such as cognitive behavioural therapy for dialysis patients also are deserving of investigation, since they have the potential to alter several psychological factors that could influence outcomes. Finally, more research is needed into identifying the information needs of patients and families. Research into prognosis and outcomes will only be practically useful if information can be appropriately conveyed to patients. We continue to need research into the best ways of delivering individually tailored information to our patients.

6.7 Conclusion

Good outcomes are not quantified merely by the number of days survived or hospitalisations avoided – rather, a good outcome is one that meets the expectations of the patient and allows patients to continue their lives with the least possible disruption. The results of my research show that clinicians can help their patients by providing realistic information about all the possible consequences of the different treatment options. Patients need to be well-informed; they want information about prognosis as well as about quality of life with treatment. They desire to be treated with respect, and as valuable individuals who have a say and sense of control in their health care. While several adverse consequences of renal disease and dialysis treatment are inevitable, outcomes could potentially be improved when well-informed patients undertake treatment with realistic expectations, when proactive efforts are made to improve their quality of life and preserve functional status, and when patients are supported by a reliable network of carers and professionals.

Appendices

Appendix 1 : Supplements to Chapter 2

Table A-14: Final data extraction form for included articles with examples

Author/ Year	Outcome /Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings _ Comment
Forzley, 2018	Prognosis: Mortality	Clinical research	Prospective; Observational study; Follow up: 24 months	Cohen's score	Multicentre; Patients on HD, n= 374; Age: 68	c Stat: 0.72; but poor calibration slope 0.57 (0.3-0.83; thus crossing 0.5; P value less than 0.001) - may have limited clinical utility in settings outside of where it was derived
Kittiskulnam, 2016	Influence on quality of life	Review	Literature review	Physical functioning and frailty; cognitive function; emotional health, including depression and anxiety; and health-related quality of life.	Some elderly, but predominantly all patients with CKD, and at varying stages	Worsens QOL: emotional problems Improves QOL: treatment of anaemia, exercise, personalised alterations in dialysis regimes
Bowling, 2017	Lived experience	Clinical Research	Qualitative analysis; Six focus groups were conducted	Challenges older adults face in maintaining CKD self-manageme	Single centre; patients on HD; n= 30 Age: >70	1. Complexity: multiple medical conditions, complex regimen of recommendatio

				nt regimens.		ns, sometimes discordant. 2. Prioritisation is a strategy for managing complexity
Harwood, 2014 [228,]	Informati on needs	Clinical Research	Qualitative analysis; Ethnograp hy; critical realism	Personal and structural facilitators and barriers for home-dialysis decision-making	Single centre; Patients from a multidisciplina ry CKD clinic as well as the healthcare professionals. n= 13 patients, 4 HCPs Age: >65(mean 74.3)	About dialysis; its effects on lifestyle; the need for support; the difference in information seeking behaviours Themes: precariousness with limited choices; personal factors (age, knowledge about dialysis; lifestyle and effects of dialysis; learning their options); gender differences in approach to learning (men did not seek the information; tends to delay decisions); the necessity of support

Table A-15: Example of Search Terms used in databases: Pubmed

Description	Search terms used
Renal failure / Dialysis / Supportive care	((((("Renal Insufficiency, Chronic"[Mesh]) OR "Kidney Failure, Chronic"[Mesh]) OR "Renal Dialysis"[Majr]) OR "Kidneys, Artificial"[Mesh]) OR (((((((supportive[Text Word] OR conservative[Text Word])) AND chronic renal insufficiency[MeSH Terms])) OR ((((supportive[Text Word] OR conservative[Text Word])) AND renal dialysis[MeSH Terms]))) OR (((supportive[Text Word] OR conservative[Text Word])) AND chronic kidney failure[MeSH Terms]))))))
Older subjects	((((((elderly[Title/Abstract] OR elder[Title/Abstract] OR old[Title/Abstract] OR older[Title/Abstract])) OR aged[MeSH Terms]) OR (aged, 80 and over[MeSH Terms])))
Prognosis	(((Survival[Text Word] OR "survival rate"[Text Word] OR "survival analysis"[Text Word] OR Prognosis[Text Word] OR "proportional hazards model"[Text Word] OR "Kaplan-Meier estimate"OR "time factors"[Text Word] OR "treatment outcome"[Text Word])))
Quality of life	(((((((((Activities of Daily Living[MeSH Terms]) OR Health Status Indicators[MeSH Terms]) OR Adaptation, Psychological[MeSH Terms]) OR Health Status[MeSH Terms]) OR Patient Satisfaction / statistics & numerical data[MeSH Terms]) OR quality of life[MeSH Terms]) OR Severity of Illness Index[MeSH Terms]) OR (surveys and questionnaires[MeSH Terms])) OR Psychiatric Status Rating Scales[MeSH Terms]) OR principal component analysis[MeSH Terms]
Lived experience	((((((((((((((((((((Adaptation, psychological[MeSH Terms]) OR attitude to health[MeSH Terms]) OR advance care planning[MeSH Terms]) OR (Behavior and Behavior Mechanisms[MeSH Terms])) OR decision-making[MeSH Terms]) OR Life style[MeSH Terms]) OR health knowledge, attitudes, practice[MeSH Terms]) OR Delivery of Health Care[MeSH Terms]) OR role[MeSH Terms]) OR needs assessment[MeSH Terms]) OR Patient Education as Topic[MeSH Terms]) OR Attitude to Health[MeSH Terms]) OR Patient satisfaction[MeSH Terms]) OR patient preference [MeSH Terms]) OR Health Care Evaluation Mechanisms[MeSH Terms]) OR (religion and psychology[MeSH Terms])) OR (surveys and questionnaires[MeSH Terms])) OR Sociological Factors[MeSH Terms]) OR Social Work[MeSH Terms]) OR

	uncertainty[MeSH Terms]) OR "lived experience"[Title/Abstract]))
Information needs	((("information needs"[Title/Abstract]) OR information[Title/Abstract])) OR ((((((((((((((((((((Attitude[MeSH Terms]) OR "Caregivers/psychology"[Mesh]) OR "Algorithms"[Majr]) OR "decision making"[MeSH Terms]) OR ("Chronic Disease/psychology"[Mesh] OR "Chronic Disease/therapy"[Mesh])) OR Communication[MeSH Terms]) OR Comprehension[MeSH Terms]) OR Cost of Illness[MeSH Terms]) OR Computers, Handheld[MeSH Terms]) OR Decision Support Techniques[MeSH Terms]) OR "Decision Support Systems, Clinical/instrumentation"[Mesh]) OR Mobile Applications[MeSH Terms]) OR Needs Assessment[MeSH Terms]) OR Patient Education as Topic[MeSH Terms]) OR Patient Satisfaction[MeSH Terms]) OR (Surveys and Questionnaires[MeSH Terms])) OR "Withholding Treatment"[Majr]) OR Health Behavior[MeSH Terms]) OR Health Literacy[MeSH Terms]) OR life style[MeSH Terms]) OR transportation of patients[MeSH Terms])
Filters	Publication date from 2000/01/01 to 2018/08/31; Humans; English; Adult: 19+ years
Example of combinations of search terms for articles on prognosis	((((((("Renal Insufficiency, Chronic"[Mesh]) OR "Kidney Failure, Chronic"[Mesh]) OR "Renal Dialysis"[Majr]) OR "Kidneys, Artificial"[Mesh]) OR (((((((supportive[Text Word] OR conservative[Text Word])) AND chronic renal insufficiency[MeSH Terms])) OR ((((supportive[Text Word] OR conservative[Text Word])) AND renal dialysis[MeSH Terms]))) OR (((supportive[Text Word] OR conservative[Text Word])) AND chronic kidney failure[MeSH Terms])))))) AND (((((((elderly[Title/Abstract] OR elder[Title/Abstract] OR old[Title/Abstract] OR older[Title/Abstract])) OR aged[MeSH Terms]) OR (aged, 80 and over[MeSH Terms])))))) AND ((((Survival[Text Word] OR “survival rate”[Text Word] OR “survival analysis”[Text Word] OR Prognosis[Text Word] OR “proportional hazards model”[Text Word] OR “Kaplan-Meier estimate”OR “time factors”[Text Word] OR “treatment outcome”[Text Word])))) Filters: Publication date from 2000/01/01 to 2018/08/31; Humans; English; Adult: 19+ years

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	37 (Title)
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	37
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	39,40
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	41
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	40; Ch. 2.1
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	41–42
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	42
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	148
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	41– 44
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	45,146
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	42–43
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N.a.
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	43

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Fig 2-1, page 44
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Pages 7,8; supplementary files 2, 3
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	153
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	45 – 68
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	69 – 73
Limitations	20	Discuss the limitations of the scoping review process.	72
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	73
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N.a.

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. ;169:467–473. doi: 10.7326/M18-0850

Table A-16: Summary of Studies Included in Scoping Review

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Abdel-Rahman, 2011 (287)	Prognosis: Mortality	Clinical research	Prospective; Observational study; Patients > 65; Follow up: 66 months or until death	Depression by Beck's depression inventory	Single center; HD patients > 65; n= 89; Age:73.5 ± 6.2;	Depression in 41%; Those > 65: No statistically significant effect of depression on mortality; unlike effects seen in younger people
Alfaadhel, 2015 (283)	Prognosis: Time to death	Clinical research	Prospective; Observational study; Follow up: 20 months	Clinical frailty scale	Single centre; Incident HD patients; n= 390; Age: 63±15	Frailty scores were normally distributed. Advanced age, comorbidity, and dialysis modality did not affect the association between frailty and mortality. In an adjusted Cox survival analysis, each 1-point increase in the CFS score was associated with a relative mortality HR of 1.22 (95% CI, 1.04 to 1.43;P =0.02)
Arai, 2014 (288)	Prognosis: Survival at six months	Clinical research	Retrospective Observational study; Follow up: 5.6±1.1 months	Mobility	Single centre; patients hospitalised for RRT start; divided into 3 groups , based on mobility, for comparison; n= 202; Age: 80.4±4.3	Those with preserved mobility in initial admission had better survival.
Balogun, 2011 (289)	Prognosis: Mortality	Clinical research	Prospective; Observational study; Follow up: 35.2 (8–66) months	Geriatric depression Scale	Single center; HD patients n= 77; Age: > 65	Survival: No depression: 79.9%, 63.5% and 52.9% at 1, 2 and 3 years with depression: 72.2%, 47.1% and 38.5% Median survival with depression 23 months, without 45.2 months; aHR 1.91

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Bansal, 2015 (118)	Prognosis: 5-year mortality	Clinical research	Retrospective Observational study; Follow up: 60 months	Demo-graphic variables, physical examinatio n measures and laboratory values selected from 16 candidate variables	Older patients with CKD; in inception and validation cohorts selected from two different studies; n= 8963 (5888 from a cardiovascular study for the development cohort and 3075 from another study for the validation cohort); Age: > 65	Final multivariate model, significant associations with five your mortality: older age, men, white race, lower EGFR, higher UA CR, diabetes, tobacco use and history of heart failure and stroke. DC: C stat 0.72, HL 0.5; VC: C stat 0.69; HL 0.9
Brar, 2017 (290)	Prognosis: Mortality	Clinical research	Retrospective Observational study; Follow up: months Maximum of 10 years; classified for analysis into 5-year groups of age up to more than 85; and classified further into institutionalise d non-institutionalise d;	Institution alisation, comorbidit ies, age, and how they affect mortality	Registry data: Incident dialysis patients from 2001 to 2008, classified into groups; n= 394,440; Age: >70	-Institutionalisation increases the risks of mortality. -Overall survival: The mean survival was 3.11 ± 0.01 years for 70-75 years of age, 2.51 ± 0.01 for 76 - 80; 2.07 ± 0.01 for 81 - 85; and 1.59 ± 0.01 for > 85 years at the time of initiation of dialysis. Mortality at one year was 39.4% (2.55 years mean survival on haemodialysis, 2.95 years on PD.) For institutionalised patients, mean survival was 1.71, 1.44, 1.25, and 1.04 years in the various age groups, lower than the non-institutionalised; (aHR for death 1.57)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Forzley, 2018 (291)	Prognosis: Mortality	Clinical research	Prospective; Observational study; Follow up: 24 months	Cohen's score	Multicentre; Patients on HD, n= 374; Age: 68	c Stat: 0.72; but poor calibration slope 0.57 (0.3-0.83; thus crossing 0.5; P value less than 0.001) - may have limited clinical utility in settings outside of where it was derived
Brown, 2015 (139)	Prognosis: Survival, quality of life, Lived experience	Clinical research	Prospective Observational Study; Follow-up 16 months Survey based: SGA; MSAS-SF; POS-r; SF 36 Clinical, laboratory, socio-demographic variables	Age, biochemical parameters and effect on Survival, symptoms and quality of life in patients managed without dialysis in a dedicated supportive care pathway	Single centre; Pre-dialysis and not-for-dialysis decision groups followed; Patients planning dialysis (n= 273); patients on conservative management (n= 122; Age: 82±9) and patients starting dialysis without attending the predialysis clinic (n= 72).	Age, albumin, GFR - had the greatest impact on survival More Symptoms in CM; 57% had improved symptoms over 12 months No significant QOL differences in the 2 groups (except for lower PCS in CM at start) 58% had stable QOL with CM over 12 months.
Carson, 2009 (135)	Prognosis: Mortality from a threshold GFR of 10.8; Hospitalisation, Place of death.	Clinical research	Prospective; Observational study; Follow up: - n.a.	Descriptive study; comparing CM to RRT	Single centre; All older patients in clinic; n= 202 (173 on RRT, 29 on CM); Age: >70	Survival: RRT vs CM: 37.84 vs 13. 9 months RRT-more hospitalisation, more hospital days per by patient days survived CM-more likely to die at home or in a hospice
Chandna, 2011 (136)	Prognosis: Mortality	Clinical research	Retrospective Observational study; Follow up: Up to 18 years	Age, comorbidity and Gender; compariso	Single centre; All patients with CKD stage V seen over a period of 18 years In	CM was older and had greater comorbidities. Survival (median) with low comorbidity:

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
				n of CM and RRT	a Canadian Centre. n= 844 (CM 155, RRT 689); Ages: CM 77.5± 7.6; RRT 58.5±15;	less in CM (29.4 Vs.36.8 months) Survival, severe comorbidity: less in CM (20.4 Vs.25.8 months) (non-significant difference in survival with severe comorbidity). In those > 75 with severe comorbidity, no significant survival advantage for RRT over CM.
Chandna, 2016 (142)	Prognosis: Survival and treatment choices	Clinical research	Retrospective Observational study; minimum 3 years	Rate of kidney function decline; comorbidities	Single centre; Patients with GFR between 10 and 15, cohort chosen between 1995 and 2010; n= 250; Age: 80.9±4	Rate of decline of GFR: -more rapid in those choosing dialysis (0.45 ML per month) vs CM (0.21 ML); marker of mortality in CM Patients with high comorbidity on RRT: nonsignificant survival advantage of five months; CM cohort: similar age, more comorbidities, but slower rate of decline in eGFR. Survival: less in CM (23.1 vs 38.2 months) Survival with high comorbidity: less in CM (20.3 vs 28.4 months) CM choice was more likely in age> 75, females, high comorbidity or low rate of decline of eGFR."

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Chauveau, 2001 (292)	Prognosis: Survival	Clinical research	Nutritional, dialysis adequacy and epidemiology factors	Nutritional, dialysis adequacy, epidemiological and biochemical factors	Multicentre; Patients on dialysis; n= 290; Age: 79.8±4.2	Overall survival rates were 80% and 65% after one and two years of follow-up; Univariate: age, albumin, pre-albumin, body mass index, diabetes had influence. Multivariate: none significant
Chen, 2017 (130)	Prognosis: 5-year survival (as fitness for transplant)	Clinical research	Retrospective Observational study; Follow up: 60 months	Predictors of five-year survival; so as to be eligible for transplant; Predictive model (9 variables, including: Age, gender, race, primary disease, BMI, employment status, previous renal care, dialysis access, comorbidities)	USRDS database; derivation and 2 validation cohorts; n= 159362; Age:>70	Age was the strongest predictor. (age more than 85) Other predictors: increased mortality-80 to 84, BMI below 18, being institutionalised. Reduced mortality-non-white race; non-diabetes ESRD; being employed; presence of AVF Best survival with the score less than -4 c-statistic IC: 0.71 (0.70-0.71) VC 1: 0.71; VC 2: 0.60 (0.57-0.63: poor discrimination)
Cherukuri, 2010 (293),	Prognosis: Survival	Clinical research	Prospective; Observational study; Follow up: 4.7±0.6 years	Age, biochemical factors	Single centre; Patients on HD; n= 94; Age: 63±15.6; 56% over 65 years	Poor survival: Vascular disease, calcium phosphate product, diabetes mellitus; low haemoglobin and lower initial pre-dialysis eGFR
Cheung, 2014 (111)	Prognosis: Mortality-odds of death	Clinical research	Retrospective Observational study; Follow up: 6 months	Three prognostic indices - the Liu	Registry data (USRDS); n= 44,109; Age: > 67	23.3% died in six months. Older patients had more: impatient starts,

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
	associated with each prognostic index, with and without adjustment for age			index; the French Renal Epidemiology and Information Network score; and hospice eligibility criteria score		hospitalisations, nursing home state, for mobility, low BMI or malnutrition. C statistics declined with older age; therefore, indexes are probably not useful. None of the indexes had high sensitivity and specificity.
Chua, 2014 (120)	Prognosis: One-year mortality; 90-day mortality	Clinical research	Retrospective audit of a patient database; age recorded as less than 70 or more than 70; Follow up: 12 months	UREA5 score (age, biochemistry, ejection fraction) - see chart in main text [URate, EF, Age, Arteriopathy-PVD or CVA Albumin, ALP]	Single centre; ESRD patients newly initiated on haemodialysis or peritoneal dialysis 2005 to 2010; n= 983; Age: 60±13	90-day mortality- 6.7%; further 10.5% died between 90 days to one year first year mortality- 17.2%; older, more comorbidities, poor LVEF parameters: Score greater than five - 46% first-year mortality; C statistic 0.74 for first-year mortality; C statistic 0.8 for 90-day mortality
Cohen, 2010 (294)	Prognosis: 6-month mortality	Clinical research	Prospective observational study; multivariate Cox proportional hazards model by using the stepwise selection based on the values in the univariate pathway; Follow up: 6 months	Age, dementia, peripheral vascular disease, decreased albumin and surprise question	Multicentre; Prevalent haemodialysis patients (not incident); n= 1028; Age: 61 ± 17	Score: AUC: 0.87 for six months; 0.77 across all time aHR: Surprise question 2.71; one-unit albumin increase 0.27; age: for a 10-year increase 1.36; therefore, adversely disease 1.88; dementia 2.24

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Conway, 2009 (295)	Prognosis: Risk of developing RRT	Clinical research	Retrospective Observational study Follow up: 3.76 years	age, proteinuria, rate of fall of GFR, haemoglobin	Multicentre; local database Pre-dialysis patients with stage 4 CKD seen in nephrology clinic from 1998 to 2002; n= 396 Age: 71.6; more than one third older than 75	Risk of surviving to require dialysis fell with increasing age (HR 0.44; 0.23-0.84) for those over 74 vs those less than 65 due to a slower rate of GFR decline. Other factors predicting RRT: baseline proteinuria, rate of decline of renal function, baseline GFR, haemoglobin
Coric, 2015 (296)	Prognosis: Mortality	Clinical research	Retrospective Observational study via analysis of medical records; Follow up: 36 months	Anaemia, hypoalbuminemia, CRP, Vascular access	Single centre; All patients on haemodialysis, with those over 65 compared to the others. n= 232 Age: mean age: female 64, male 59	Age affected specific mortality rate: < 65 : 16.8%, and > 65: 50.5% According to the age groups the mortality rate: 65 – 74 years : 45.1%; 75 – 84 years 55.0%, ≥85 years: 75.0%
Couchoud, 2009 (123)	Prognosis: 6-month mortality	Clinical research	Multivariate logistic regression with 500 bootstrap samples allowed us to select risk factors from 19 demographic and baseline clinical variables.	Body mass index, Total dependency for transfers, unplanned dialysis, comorbidities; All variables obtained at initiation of dialysis	REIN registry data; training (n= 2500) and validation (n= 1642) cohorts n= 3142 (in total) Age:>75	Nine risk factors were selected and points assigned for the score were as follows: body mass index < 18.5 kg/m (2 points), diabetes (1), congestive heart failure stage III to IV 2 (2), peripheral vascular disease stage III to IV (2), dysrhythmia (1), active malignancy (1)severe behavioural disorder (2), total dependency for transfers (3) and unplanned dialysis (2). C statistic: IC - n.a., VC: 0.7;HL test P

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						value: 0.93; good transportability to 3 & 12 months
de Jager, 2011 (297)	Prognosis: 1-year Mortality	Clinical research	Prospective Observational study Follow up: 12 months Mortality adjusted for age, sex and primary kidney disease	Time between first visit to nephrology clinic and initiation of dialysis (i.e., time of referral)	Multicentre (data derived from larger study) All patients who initiated dialysis; classified as : Those late (<3 months), early (3 –12 months) or very early (≥ 12 months) based on time between first nephrology visit and dialysis start. n= 1438 Age: >70 compared to <70	Those ≥ 70 years had higher mortality rates compared to <70 years [HR 2.6 (2.0, 3.5)]. Delayed referral: 1-year mortality – AHR 3.2 - 5.4 compared to early referrals in < 70
de Jonge, 2003 (298)	Prognosis: 1-year mortality, Influence on quality of life	Clinical research	Prospective Observational study Follow up: 12 months Surveys used: INTERMED scale; SF–36 (QOL) Score consisting of: Older than 65, INTERMED score >20, diabetes (one point each)	Prediction of survival and poor quality of life at one-year follow-up	Single centre; all patients initiating dialysis n= 80; Age: > 18; 40% at baseline and 32% at 1 year(survivors) were > 65.	A score > 20 - significantly associated with Mortality. Low scores "associated with quality of life". Regression models explained 32% of the variance in PCS and 40% in MCS. Risk factor for low MCS: INTERMED score Risk factor for low PCS: Diabetes, Age>65 The risk score correlated with: low PCS, low MCS and mortality

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Derrett, 2017 (299)	Prognosis: Health status at 12 months	Clinical research	Prospective longitudinal cohort study; Asked the single question "compared to one year ago how would you rate your health in general now?" modified Poisson regression analysis	36 item Short form health survey, EQ 5D, kidney symptoms score	Multicentre (data from larger study) Elders in the DOS 65+ study on haemodialysis n= 150 Age:>65	35% reported worse health or had died at 12 months. Reduced risk for worse health status : Pacific ethnicity(RR 0.83) , greater bother on the Kidney Symptom Score and dialyzing at home with either home hemodialysis (0.55) or peritoneal dialysis (0.86) Increased risk : social dissatisfaction (1.66) lower sense of community (1.7) , comorbid conditions (1.7) EQ-5D anxiety/depression (1.6); poor/fair overall general health rating (1.6) , and longer time on dialysis therapy (1.03)
Dimkovic, 2015 (300)	Prognosis: Survival, Achievement of guideline targets	Clinical research	Prospective Observational study Follow up: 12 months	Demographics biochemistry	Multicentre; all patients on haemodialysis n= 715.(total: 2153; >65: 715) Age: 72.4 ± 4.9 (Older than 65 compared to younger than 65)	Among targets, only PTH had an effect on mortality in the older. Older people less likely to achieve targets for Hb, not for others. gender, dialysis vintage and PTH affected survival.
Drawz, 2013 (85)	Prognosis: Onset of ESRD (Initiation of dialysis, ICD code, eGFR <15)	Clinical research	Retrospective Observational study Follow up: 12 months Final model using backward stepwise selection; comparison to	eGFR, age, CHF, blood pressure, potassium, albumin	Single centre; older patients with CKD stage 4 and below seen in an Outpatient clinic; n= 2685 (development-1866,	The final model included index eGFR, age, CHF, average of last five clinic systolic BP measurements, most recent potassium and albumin, and interactions between age and eGFR and eGFR and CHF.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			C statistic based on Tangri model		validation- 819) Age: >65	c-stat - 0.854, compared well to Tangri score
Dusseux, 2015 (127)	Prognosis: 3-year survival	Clinical research	Logistic regression	Predictive model (14 variables - including age, gender, body mass index, comorbidities, mobility, and temporary catheter at start.)	REIN registry data Elderly incident dialysis patients n= 16,337 (-8995 derivation and 7382 validation cohorts); Age:78 (range 74-– 82)	Good discriminatory ability for the predictive model of elderly people likely to have survival >70% at 3 years (and therefore are good transplant candidates); C - Statistic IC: 0.71 (0.69-0.71); VC: 0.71 (0.70-0.72); HL test P value- 0.2
Echevers, 2016 (141)	Prognosis: Survival	Clinical research	Retrospective Observational study ; Cox proportional hazards; multivariate analysis Follow up: 60 months	GFR, mode of treatment (CM vs RRT), length of follow-up in nephrology.	Single centre; All patients 70 or older attending nephrology clinic with CKD stages four and five. n= 314 Age:77 (range 74 – 81)	Survival Advantage not significant in those over 80. Cox: being on dialysis, follow-up period, Baseline kidney function Survival (overall study duration): less with CM (39 vs 65 months) Survival from eGFR<15: less with CM (21 vs 46 months) Survival in those > 75: less with CM (p=0.003) Survival in those > 80: no difference between CM vs RRT Survival in those with IHD - no difference between CM vs RRT Survival with high comorbidity CCI score: less with CM (p=0.009)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Ellam, 2009 (301)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow-up: up to 4 years	Albumin; renal referral; comorbidities	Single centre; older patients electing conservative management, divided into two groups based on whether they received nephrology care before CKD 5 n= 69 Age: Median 80	Overall median patient survival from the time of first known CKD 5 was 21 months. Patients known to a nephrologist survived longer (32 vs 15 months) S. albumin > 35 – greater survival; no effect for comorbidities
Farragher, 2014 (302)	Prognosis: Mortality; Lived Experience	Clinical research	Prospective cohort study, Follow up: 20.4 months Multivariable random effects Poisson regression	Age, history and number of falls, gender, time on dialysis, visual impairment, functional status	Multicentre; Patients on peritoneal dialysis, those falling (40) vs non- falling (34) n= 74 Age:76.2 ± 7.5	Adjusted mean fall rate: 1.7 falls per patient-year; Patients with falls: more likely to be men, older , have higher comorbidity, be recently initiated onto dialysis, more likely to have fall in the previous 1 year, history of fractures or visual impairment, more dependent at baseline. a HR 1.62 (1.29-2.02) for number of all falls
Floege, 2015 (132)	Prognosis: 1- and 2-year mortality	Clinical research	Retrospective Observational study Follow up: Two years maximum	Predictive model (14 variables including: Age, smoking, BMI, comorbidities, Dialysis parameters, biochemistry)	Multicentre; of all incident patients from a European patient database (AROii) between 2007 and 2009; validated in a population of incident and prevalent patients	Sensitivity 70 to 80%; specificity 66 to 56% for one year and two-year mortality respectively; Validated in the DOPPS cohort with similar results (See table in main text)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					Only including incident patients within four days of initiation n= 10,615 age: 63.4± 14.3 Creatinine: 777.9± 256.4 Baseline data obtained at < 3 months of initiation in the DOPPS III cohort	
Foote, 2012 (303)	Prognosis: Mortality	Clinical research	Prospective Observational study Follow up: 2.3 years (1.1-3.3) Multi variable proportional hazards model	Demographics, comorbidities, referral, access, intended modality	Registry data (ANZDATA); all patients over 75 beginning dialysis from 2002 to 2005. n= 79 Age:79 (range 77 – 81)	Overall mortality 65%; one- and two-year survival rate is 76.9 and 59.3 percent. Adjusted HR: five-year increments of age (1.24) comorbid conditions >3: 1.89, being underweight 1.78, PD vs HD 1.26, later referral 1.19, unprepared access at first dialysis 1.43, all with confidence intervals
Foote, 2016 (304)	Prognosis	Meta-analysis	Meta-analysis		Studies up to 2014: 294,921 elderly renal failure patients; 724 supportive care patients	1-year survival for elderly patients treated with: undifferentiated dialysis — 73.0% (66.3–79.7%), haemodialysis: 78.4% (75.2– 81.6) peritoneal dialysis: 77.9% (73.8–81.9) Supportive care : 70.6% (63.3–78.0%). Residual heterogeneity remained.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						Broadly similar 1-year survival in elderly ESKD patients, it does not allow a confident estimate of the relative survival benefits of dialysis or supportive care.
Fukasawa, 2017 (305)	Prognosis: Mortality over four years	Clinical research	Prospective Observational study	Muscle mass and fat mass	Single centre; Patients on dialysis n= 81 Age: 67 (range 60 — 73)	Lower thigh muscle mass is significantly associated with all-cause and cardiovascular mortality in hemodialysis patients. Each 0 .1 cm^2 per KG increase in muscle mass : 22% lower risk of all-cause mortality and a 30% lower risk of cardiovascular mortality
Fukuma, 2017 (133)	Prognosis: Loss of physical function in 12 months	Clinical research	Prospective Observational study Follow up: 12 months	Predictive model. (6 variables included: Age, gender, dementia, mental health, moderate activity and ascending stairs); 12-item Short form health survey physical function score	Study data: Dialysis patients part of the J-DOPPS; inception and validation cohorts n= 1040 (IC: 593; VC: 447) Age:>65	c-statistic IC: 0.79 (0.74-0.84) VC: 0.76 (0.72-0.8) Well calibrated

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Genestier, 2010 (306)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: Up to four years Multivariate analysis; No competing risks.	AGGIR, ADL score, clinical variables, PD parameters	Single centre; All elderly peritoneal dialysis patients between 1997 and 2006 July n= 112 Age:81.3 ± 4.2	More dependence in the older age groups (28 to 30%). mean survival: 19.6 (13.9) months, median 18 months. Survival at 1, 2, and 3 years was 64.9%, 40.6% and 14.9% respectively. aHR - AG GIR group 0.88 (0.76-1.02); early referral 0.45 (0.28-0.73); Charlson comorbidity index 1.18 (1.04-1.35; institutionalised 4.84 (2.13-10.98); poly medication 2.16 (1.2-3.88).
Gubensek, 2014 (307)	Prognosis: Mode of start, mortality	Clinical research	Retrospective chart review Follow up: 7 years	Age, prior nephrology care (3 months before dialysis start)	Registry data, all patients older than 80 starting dialysis between 2004 and 2010; n= 170 Age:83 (range 81 – 85)	55% of patients died. Median survival 26 months; 1, 2- and 3-year survival rates: 74, 52 and 41% aHR for mortality: age 1.10, being seen by nephrologist 0.48
Hatakeyama, 2013 (308)	Prognosis: Mortality	Clinical research	Retrospective Observational study; chart review Follow up: "Until death or end of study"	ECOG performance status; haemoglobin	Single centre; 1144 consecutive patients; those over 80 were studied. Patient survival compared to general population survival in the same age groups. n= 141 Age: 84.2 ± 3.1	Median survival time was 2.6 years (Lowest in those over 90: 0.9 years) Mean life shortening: 5.3 years ≥ 80; 9.4 years 70 – 79; 14.6 years 60 – 70 Cause of death: infectious disease 33%, cerebro-cardiovascular disease 27% Optimal cut-off points: ECOG greater than one; haemoglobin less than 9.55

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Holme, 2012 (309)	Prognosis: Mortality over 3 to 4 years in a medium risk population	Clinical research	Prospective Observational study Follow up: 3.8 years model tested for improvement by adding other candidate variables; calibration and discrimination assessed; Cox regression analysis; HL; no competing risks mentioned	5 empirically selected factors: Age, albumin, CRP, history of cardiovascular disease, diabetes	Population drawn from the database of cardiovascular study. Validation cohorts were internal. n= 1868 Age: 66.6 (8.5) and those who died; 61.9 (8.1) in survivors	Age was the strongest risk factor. Addition of other factors did not make major changes. C stat - 0.72 (0.7-0.75) ; HL good No comparing risks mentioned no external validation. Selected population is a medium risk, randomised population
Hoogeveen , 2017 (310)	Prognosis: Risks of dialysis and mortality (cumulative)	Review	Prospective Observational study Risk of dialysis and risk of death (as competing risk); both together as a cumulative outcome. Patients grouped into four categories of BMI and two age categories (>65, <65) Follow up: 16 (7-32) months	BMI, Age group (>65, <65)	Multicentre; pre-dialysis patients. n= 492 (280 were > 65) Age:65 ± 14	U-shaped relationship between BMI and cumulative outcome aHR for combined endpoint in those > 65 : low BMI - 1.73, high BMI - 1.3 compared to normal BMI

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Hung, 2009 (311)	Prognosis: Mortality; technique survival; comparison with haemodialysis	Clinical research	Retrospective Observational study Multivariate regression Follow up: 5 months	Functional dependence, diabetes, previous haemodialysis, serum albumin	Single centre; Patients over 65 starting CAPD between 1985 and 2004. n= 144 (of 900 patients) Age:>65	Factors influencing survival - diabetes, previous haemodialysis, dependent patients, albumin levels. Gender not important in multivariate analysis.
Hussain, 2013 (16)	Prognosis: Survival; Lived experience	Clinical research	Retrospective Observational study Follow up: not specified Database of records analysed by independent researcher Surveys used: Davies et and Charlson's Comorbidity Index (CCI) scores, and the World Health Organization (WHO) performance score for functional status	RRT vs CM, comorbidities, WHO performance score, hospital admissions and palliative care access	All patients aged >70 and eGFR <20 receiving advice regarding CM vs RRT during pre-dialysis education. Survival was calculated from three time points: when the eGFR was <20, <15 and <12. n= 441 (CM 172, RRT 269). Age: CM 82±5.6; RRT 77±5	(see table in main text) For survival, RRT better than CM except >80 or WHO performance score >3 Comorbidity lowered the advantage of RRT but did not abolish this. In those >80, no survival advantage for RRT over CM. In those > 70, increasing performance score or increasing comorbidities reduces the survival advantage for RRT over CM. Those accessing a conservative management pathway had greater access to palliative care services and were less likely to be admitted to or die in hospital.
Inaguma, 2017 (53)	Prognosis: Mortality, cardiovascular mortality, infection - related mortality	Clinical research	Retrospective Observational study Follow up: n.s.	Barthel index	Multicentre; Patients already on dialysis in the Aichi cohort study of prognosis in patients Classified into three based on Barthell index;	Physical functions scores at beginning of dialysis correlated with better survival, especially in those>70

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					into H, M and L scores at the time of dialysis initiation n= 1496; Age:67.4 ±13	
Isaacs, 2012 (312)	Prognosis: 5-year survival	Clinical research	Retrospective Observational study Follow up: 5 years	Age, race, albumin	Single center Patients over 80 starting dialysis in one centre between 2000 and 2009 which already has an established conservative management program. n= 93 Age: 83 (81 - 86)	Median survival 46 . 5 months (0 – 107). 1- and 5-year survival 78.5 and 38.3% Reduced with low albumin and being Caucasian
Ivory, 2017 (129)	Prognosis: 6-month mortality	Clinical research	Retrospective Observational study Follow up: 6 months	Ivory points score tool (8 variables, including: Age, weight, comorbidities, Late referral, aetiology of CKD)	Registry data; All dialysis patients; 2000-2009 for DC; 2009 to 2011 for VC; external validation in UK registry. n= 23,658 Age: 60 ± 15	Overall, six-month mortality was 6.1 %. C-statistic (HL test p value) IC: 0.751 (0.005-poor calibration) VC 1: 0.755 (0.58-acceptable) VC 2: 0.713 (0.0001-poor calibration)
Jeloka, 2011 (313)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: n.s. Basic statistics; Kaplan-Meier survival analysis; censoring patients for	Age	Single center; All patients who continue dialysis for > 1 month; Period between 2006 and 2009 ; transplanted patients excluded;	Overall median survival 60.9; elderly survival 25.6 months; younger survival 17.6 months. Elderly patients: one-year survival 68.5%; two years 41.1%.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			transplant or loss to follow-up.		n= ? Age:2 groups: >65 and < 65.	
Joly, 2003 (134)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 12 years	BMI, late referral, functional dependence, peripheral vascular disease	Single centre; All patients over 80 years old with end-stage renal disease from 1989 to 2000. n= 146 Age: 83.2 ± 2.9	37 patients 'not proposed for dialysis'; 104 were; 6 of this refused Median survival was 28.9 months in those on dialysis; 8.9 months with CM 12- and 24-month survival rates : dialysis: 73.6 and 60% and CM: 29 and 15% On dialysis: high female mortality during the first 2 years but lower mortality thereafter; short-term impact of later referral; persistent difference in survival among patients with lower Karnofsky. Negative impact of peripheral vascular disease was seen only after 18 months aHR up to 1 year and > 1 year: Late referral (2.28 and 0.68); functional dependence (2.34 and 1); per BMI (0.83 and 1); peripheral vascular disease (1.03 and 5.67)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Joshi, 2014 (314)	Prognosis: Patient survival, technique survival	Clinical research	Retrospective cohort study Follow up: 5 years	Age, comorbidity (diabetes), serum argument	Single centre; Patients on PD n= 148 were elderly Age: 71.3 ± 4.3	The 1, 2, 3- and 5-year patient survival rates were 79%, 67%, 56%, and 30% for those over 65. Survival was significantly poorer for those over 65. Technique Survival did not differ. Age 1.09, diabetes 2.06, albumin 0.94 (all relative risk)
Jung, 2017 (315)	Prognosis: Composite major adverse cardiovascular and cerebrovascular event (MA CCE)	Clinical research	Retrospective Observational study Follow up: 37.8 (3-84) months	Dementia diagnostic code	Registry data; Patients older than 65 who did not experience any CCE within 90 days from start of dialysis; n= 10,171 (303 patients had dementia). Age: >65	Survival Higher in patients without dementia (adjusted HR 1.3). aHR 1.258 adjusted HR for dementia; comorbidities important as individual predictors
Landray, 2010 (119)	Prognosis: Risk of ESRD, Risk of mortality	Clinical research	Prospective Observational Study; Follow up 4.1 (ESRD) and 6 years (death)	Prognostic models for risk of ESRD (4 variables: creatinine, phosphate, urinary albumin-creatinine ratio[UACR], female gender) and risk of death (4 variables: age, NT-pro BNP, troponin-T and cigarette smoking)	Risk of ESRD and risk of death in patients with CKD stages 3-5 in populations from 2 separate cohorts in Birmingham and East Kent, UK; n= 382; Age: 61.5 ± 14.3 EGFR: 21.8 ± 10.7 Follow up: 4.1 years and n= 213; Age: 65.1 ± 13.5	c-statistic: Prediction of ESRD: IC: 0.873 (0.836-0.909) VC: 0.91 (0.87-0.96) Prediction of death: IC: 0.82 (0.774-0.866) VC: 0.82 (0.75-0.89)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					EGFR: 21.6 ± 13.6 (Kent)	
Kallenberg , 2016 (284)	Prognosis	Review	Systematic review		Longitudinal studies of patients reaching ESRD, with measurement of functional or cognitive impairment or frailty before or after treatment initiation and adverse health outcomes after a follow-up	In 34 of 35 (97%) associations reported in the 30 included studies, functional or cognitive impairment and frailty were significantly associated with a higher risk of adverse health outcomes, independent of calendar age
Kan, 2013 (125)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: Mean 3.25 years; median 1.56 years	The New Comorbidity Index (nCI) (initially validated in dialysis populations without regard to age; 11 comorbid conditions included; age not part of the index)	Registry data; Patients on haemodialysis aged >65 n= 21,043; Age : all > 65; stratified into groups by age eGFR: n.a 52% of patients in the lowest comorbidity score group Older age groups: more men, more comorbidities.	c-stat: 0.908 (0.897-0.919); good discrimination for the index
Kanda, 2015 (316)	Prognosis: 1-year mortality	Clinical research	Retrospective Observational study Follow up: 12 months Multiple combinations tried until the	Survival index (SI) (8 variables, including age, BMI, lab data, comorbidit	Data from the DOPPS cohort; Development and validation cohorts within this population.	Most significant variables were age, BMI, creatinine, albumin, total cholesterol, phosphorus, cardiovascular disease and use of AV fistula.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			final index derived Logistic regression	ies, AV fistula use)	Incident and prevalent patients n= 7664 (IC-3899; VC-3765) Age: 62 ± 16	c-statistic: IC: 0.73; HL test p value 0.65 VC: confirmed higher risk of death in patients with low SI.
Kanno, 2017 (317)	Prognosis: 90-day and 1-year year mortality	Clinical research	Retrospective Observational study Follow up: 1 year Cox Proportional hazards	Mode of starting dialysis, hypertension, albumin, VDRA therapy	Single centre; All patients starting dialysis between 2008 and 2013 n= 122 Age: 87	aHR 90-day mortality: suboptimal start 3.98 ; hypertension 0.31; log CRP 1.12 aHR 1-year mortality suboptimal start 3.19; hypertension 0.37; albumin 0.46 ; VDRA 0.26
Kurella, 2007 (318)	Prognosis: 1-year Mortality	Clinical research	Retrospective Observational study Follow up: 1–8 years Analysis of registry data; no competing risks analysis; Cox proportional hazards	Age, mobility, comorbidities, albumin, BMI	USRDS Registry data; all older patients (>80, >90) starting dialysis; 1996 – 2003. n= 13,577 Age:84.3 ± 3.4	Increasing numbers of older patients receiving dialysis in 2003 than 1996. 1-year mortality rate is approximately 50%, this is not changed. Older age, non-ambulatory stages and more comorbid conditions were strongly associated with an increased risk for death. aHR: Non-ambulatory 1.54 ,albumin < 35 - 1.28; being underweight -1.2; congestive heart failure 1.21; ≥4 comorbidities 1.68
Kutner, 2001 (319)	Prognosis: Survival over 11 years	Clinical research	Prospective Observational study Follow up: 11 years	Race, gender, BMI	Multicentre study; Patients on dialysis n= 316 Age: 68.4 ± 5.7	Relative risk for mortality: 0.4 for black females with higher BMI

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Kwon, 2012 (320)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: ns Conference abstract	HbA1c levels	Multicentre; Patients initiating dialysis n= 65 Age: >75	Median survival from initiation of dialysis was 29 months; Adjusted HR 4.66 (1.79-12.16) Diabetes per se was not a risk factor for mortality however uncontrolled diabetes mellitus was.
Lamping, 2000 (321)	Prognosis: 1-year Survival, Influence on quality of life	Clinical research	Prospective observational study Follow-Up: 12 months	Age, gender, treatment modality, time of referral, comorbidities, costs	Multicentre; Patients who started HD during the study period to assess for survival; patients already on HD for disease burden n= 221 Age:>70	71% one-year Overall survival; 54% in those over 80; 71% in 75-80; 88% in 70-74. Age, gender, modality, late referral, and comorbidities affected survival (0.56 to 2.97). Despite being on HD, MCS similar to general population; PCS was lower.
Lee, 2014 (322)	Prognosis: Survival	Clinical research	Prospective Observational study Follow up: 37.8 (3 to 84) months Multivariate proportional hazard model	Age, gender, dialysis modality, type of insurance, comorbidities	Korean administrative data; study of elderly pre-dialysis patients n= 11,301 Age: 71.9 ± 5.4	aHR - 1.05 to 1.48 for most variables; Malignancies, Cerebrovascular disease and dementia carried higher aHR. Survival significantly higher in HD in this study (but no description of differences in the groups; no discussion of confounding factors; 81% of population chose HD over PD)
Lee, 2017 (323)	Prognosis: All-cause mortality; cardiovascular hospitalisation(as a	Clinical research	Prospective Observational study Follow up: 17.7 months	CGA	Single centre; elderly patients at a dialysis centre n= 46 Age: 71.5	aHR (for composite outcome, not just mortality) 23.58 for frailty; other predictors include age, gender, diabetes, body mass index, pre-

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
	composite outcome!)					dialysis nephrology care
Leimbach, 2015(324)	Prognosis: Mortality at 1, 3, 5, and 10 years	Clinical research	Retrospective Observational study Follow up: 10 years	At least three months of predialysis nephrology care	Single centre; All patients > 80 who started HD between 2001 and 2012 n= 76 Age: 82 (80-91)	One-year survival was 87%, three-year survival 52% and 10-year survival 9%. Those with <3 months pre-HD care: died within 7 years. With >3 months pre-HD care: 5-year survival – 37% and 10-year – 18%. Significant difference on survival (if pre-dialysis care was more than three months)
Lertdumrongluk, 2013 (325)	Prognosis: All-cause and cardiovascular mortality	Clinical research	Retrospective Observational study Follow up: 2.21 (1.18-3.68) years	Time-averaged Phosphorus levels	Multicentre; Patients on dialysis; Data extracted from medical records; Stratified for age n= 107817 Age: 60±16	High and low levels associated with mortality The association between hyperphosphatemia and mortality is similar across all age groups of MHD patients, whereas hypophosphatemia is associated with increased mortality only in elderly. aHR Low: 1.13 – 1.37; high: 1.41 – 2.77
Letourneau, 2003 (326)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 6 years Multivariate logistic regression to find risk factors	Hospitalisations, lower weight, age, Clinical, laboratory, sociodemographic	Single center; All patients beginning dialysis over 75 years of age between 96 and 2000; one group over 75 (67 patients) and	Older patients were: referred late, HD rather than PD, on catheters, no transplants, less likely to change modality. One-year survival: 80% vs 93% 3-year survival: 45% vs 74%

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			influencing survival; Kaplan-Meier curves for mean survival time	data collected.	another group between 50 and 60 (66 patients) were compared. n= 67 Age: >75	OR for mortality : > 75 years old: 2.66, more than 30 days in hospital: 34.85; weight <58 KG: 16.56
Li, 2008 (327)	Prognosis: Mortality	Clinical research	Prospective Observational study Follow up: 32.7 (14 to 57) months	Falls	Multicentre; Patients on dialysis from 2002-2003 n= 162 Age:74.7±6.1	Patients with falls are more likely to be older, more comorbidities, diabetic, recently started dialysis. aHR 1.63 (1.02-2.28)(After falls due to other causes were excluded)
Lin, 2013 (328)	Prognosis: Mortality, hospitalisation, costs	Clinical research	Retrospective Observational study; Follow up: 10 years	age, comorbidity score(Deyo - Charlson comorbidity index)	Patients who started HD between 1998 and 2007 in Taiwan; Patients classified by age (5-year groups) and CCI (3 points) and mortality compared	predictors of survival: Age, higher CCI values Increased costs and mortality rates in the oldest patients and in those with high CCI scores. Increasing age aHR: 1.37 to 2.27. Increasing CCI: 1.39 to 2.64
Lin, 2013 (329)	Prognosis: All-cause mortality; cardiovascular outcomes	Clinical research	Prospective observational study; multivariate analysis, Kaplan-Meier method	P cresyl sulphate and indole sulphate, comorbidities	Single center; stable patients on HD; classified as above and below the median level of p-cresyl sulfate n= 55; Age:70.5 ± 3.45	Increasing levels of uraemic toxins may have an effect on mortality aHR: free p-cresyl sulfate 1.66; total p-cresyl sulfate 1.34; presence of diabetes 0.16
Madziarska, 2012 (330)	Prognosis: Mortality	Clinical research	Prospective Observational study Follow up: 4 years	Plasma pro-ANP, blood pressure, residual urine, BMI	Multicentre; Prevalent elderly dialysis patients n= 51 Age:77	Poor survival: lack of residual urine Higher ANP: lowered systolic BP

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Mauri, 2008 (331)	Prognosis: 1-year mortality	Clinical research	Population randomly divided into development and validation cohorts	Predictive model - 10 variables – including age, gender, primary renal disease, functional status, comorbidities, and malnutrition	Registry data; all patients who started HD from 1997 – 2003 and had a follow up of at least one year n= 5738 Age: 64.6 ± 14.4	Overall mortality was 16.5%. Main effect variables: sex, age, primary renal disease, functional autonomy degree, cardiovascular disease, COPD, malignant processes, chronic liver disease and malnutrition C statistic for model: 0.78
McAdams-DeMarco, 2012 (332)	Prognosis: Survival In those over 65	Clinical research	Prospective study; Follow up: 24 ± 6.9 months	ADL disability (AHR value); model consisting of this and age sex and number of comorbidities	single centre; patients on HD n= 143 Age: 60.6 ± 13.4	aHR 3.46 (1.22-9.77) for disability; C statistic of 0.74 for the model Comorbidities, age and gender, disability included in the final proportional hazards model
McKercher, 2014 (333)	Prognosis: Survival	Clinical research	Retrospective cohort analysis Follow up: 26.9 (11.3 to 48.8) months	Race (indigenous vs non-)	ANZDATA Registry data; 2000 to 2011 n= 10,976 Age: >65	Indigenous patients were younger (69 vs 74); mortality rate : 23.9 per 100 pt. years(vs 21.2). Median survival time 33.8 vs 41.1 1, 3, 5, 7 and 9 survival rates were lower for indigenous patients. On multivariate analysis, race, gender, age, obesity smoking, comorbidities and late referral were significant aHR 1.2 (1.02-1.41)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Molnar, 2017 (334)	Prognosis: Mortality: 3-, 6- and 12-month and throughout follow-up	Clinical research	Retrospective cohort study; Follow up: Up to 60 months	Diagnosis of depression	Study Data from Transition of care in CKD study; Registry USRDS data; VA data; depression by validated algorithm described by Frayne, all patients on dialysis. n= 45,076 Age: 72 ± 11	23% of the cohort had depression minor increase in mortality if depression is defined by the presence of antidepressant medications Majority participants were men. aHR 1.06 (1.03-1.09) throughout follow-up period
Molnar, 2017 (335)	Prognosis: 6-month mortality	Clinical research	Retrospective cohort study Follow up: 16.2 months	Dementia diagnosis	Study data; Transition of care in CKD study; 43,740 without dementia, 1336 with dementia. Propensity matching gave a cohort of 2656 patients for survival analysis n= 1328 Age: 77.5 ± 8.9	Majority men; Low incidence of dementia overall aHR : 6-month 1.29; 12-month:1.26
Morris, 2005 (336)	Prognosis: Mortality (all-cause and cardiovascular)	Clinical research	Retrospective Observational study Follow up: 1 to 3 years	Race, Urine creatinine as a marker of nutritional status	Registry data; elderly dialysis patients > 75 n= 27304 Age:75±5.9	No major differences blacks vs whites Blacks and other races : lower risk of acute coronary events, cardiovascular death, and all cause deaths Nutritional status significant predictor Adjusted survival of whites was worse than that of Blacks with each quartile of urinary creatinine

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Munshi, 2001 (337)	Prognosis: 1- and 5-year survival	Clinical research	Retrospective Observational study Follow up: 5 years	General	Single centre; Those elderly starting dialysis 1991–1995 Population divided into : ≥ 75; 65 to 74, <65 n= 58 Age: > 75	Survival: 1-year : 53.5, 72.6, 90.6% 5-year: 2.4% 18.8% and 61.4% at five years Those > 75: spend 20% of their time in hospital; 46% had two comorbidities; 26% developed multiple complications while on RRT. Withdrawal 38%, cardiovascular deaths 24%, infectious deaths 22%
Murtagh, 2007 (74)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: 540 to 588 days Survival estimated from eGFR ≤15 to either death or study endpoint	Modality and ischaemic heart disease	Multicentre; 52 dialysis and 77 CM; Patients >75 seen in multidisciplinary clinics once decision had been made;	CM patients were older (83) compared to RRT (79.6) Median time to death: 588 for dialysis patients and 540 for CM. No survival advantage from RRT when comorbidity index was high (greater than two). Modality choice, age and comorbidity most strongly associated with survival. Overall comorbidity score and presence of ischaemic heart disease independently correlated with survival (IHD more than comorbidity). Choosing dialysis-2.9-fold better survival; IHD reduced survival by around 50%

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Nagai, 2018 (338)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 5 years Crude mortality rates for the entire population; sub- analysis by classifying into above and below 65 years old.	Age, diabetes, BMI, dialysis adequacy, biochemical parameters	Single centre; All patients on maintenance dialysis in April 2006 included. n= 735 (314 were aged over 65 and analysed separately) Age: 62.1±12.8	In those > 65: higher mortality, shorter hemodialysis duration, anaemia, lower platelet, higher β2-microglobulin, more diabetes. KT/V, serum beta-2 microglobulin and calcium concentration were independent risk factors. Strongest in multivariate model - diabetes 2.49 (1.7-3.6); high calcium 1.3 (1.04-1.6) and neutrophil count 1.2 (1.1-1.3)
O'Hare, 2007 (104)	Prognosis: Mortality, ESRD incidence	Clinical research	Prospective Observational study Follow-up: 3.2 years	Age, GFR (those ≥ 65)	Registry data; Patients in the VA system with eGFR less than 60; 97% of men study, with patients classified according to GFR and age. n= 209,622 Age:73±9	Age affected the competing risks of end-stage renal disease and death. aHR once GFR was < 30: 1.68 to 8.24 in elderly compared to those less than 45
Oliva, 2013 (339)	Prognosis: Mortality	Clinical research	Retrospective chart analysis; Follow up: Not specified; study ended December 2007 Kaplan-Meier survival curves; Cox proportional hazards: multivariate analysis.	Clinical, biochemical parameters	Registry data. Only HD Patients, who had been on dialysis for more than 90 days. Final inclusion 2601 patients, 704 patients were aged over 75 n= 704 Age:79.3	Mean survival: 46, 41.6 and 35 months in less than 60, 60-75 and more than 75. BMI <20: 1.14 -3.53; CLP more than 10: 2.19; CHF 1.57, low KT/V 1.8

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Painter, 2013 (340)	Prognosis	Commentary	Narrative review			Low levels of physical activity and poor physical functioning are strongly associated with mortality and poor clinical outcomes in adult patients with CKD, regardless of treatment modality. Low physical performance and activity limitations are more prevalent in patients with CKD, regardless of age, compared to older community-dwelling adults.
Park, 2017 (341)	Prognosis: Mortality, Cardiovascular events, quality of life, KPS, BDI, SGA	Clinical research	Prospective Observational study Follow up: 12 months	GFR at initiation	Multicentre; Database study of elderly patients. n= 665 Age: 72±5.4	Survival: No effect of initial GFR (therefore no benefit to early start) QOL: No effect at 12 months; lower PCS at three months No effects from initial GFR on : Functional status, depression, CVS outcomes
Pugh, 2016 (342)	Prognosis: Mortality; deaths prior to initiating dialysis	Clinical research	Prospective Observational study Follow up: 3 years	Charlson comorbidity index and clinical frailty scale	Single center; Patients referred for predialysis education n= 283 Age: 74 (63-81)	The CCI and CFS scores at the time of referral were independent predictors in adjusted multivariate regression models
Raimann, 2017 (343)	Prognosis: Mortality after six months	Clinical research	Prospective Observational study Follow up: 12 months Logistic regression models	Use of CVC, conversion from CVC, Demographics, geriatric nutritional index	Multicentre; Those older than 70 starting HD between 2006-2012. n= 14,966 Age: >70	Initiation with CVC and lack of conversion from CVC - both increased mortality

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Reindl-Schwaighofer, 2017 (143)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: n.s. Bootstrapping used for propensity scores.	Modality of treatment, age, gender and comorbidities	Registry data.; All patients > 65 years starting haemodialysis between 2002 and 2009 in the Austrian dialysis and transplant registry from a single hospital; compared to patients managed conservatively, after the eGFR declined <10; n= 8796 (8622 on dialysis and 174 on CM, with GFR <10). Age: >65	95% of women in the conservative group! More comorbidities, older age and the conservative group median survival time 26.9 months vs 1.1 Most significance: Initial 2 months (benefited HD); once you survive the two months, there did not seem to be much difference. Time to event analysis : Benefit of dialysis decreases with age. aHR - HD treatment: 0.23 (0.18-0.29) After two months, mode of treatment non-significant In those >65, with comorbidities, survival benefit for RRT did not persist beyond 2.9 months (females) or 1.9 months (males) compared to CM.
Roy, 2017 (344)	Prognosis: 3- and 12-month survival	Clinical research	Retrospective Observational study Follow up: 12 months	Unplanned dialysis, ischaemic heart disease and peripheral vascular disease	Single centre; Consecutive elderly patients starting HD, aged more than 75, CKD 4 or 5; not seen by nephrologists in the three months prior to initiation	Unplanned dialysis – greater mortality. Survival- unplanned vs. planned dialysis: 3 months – 38.6% vs. 90.9% ; 12 months: 14.4% vs. 73.6%

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Sakaci, 2015 (345)	Prognosis: Survival; technique survival	Clinical research	Retrospective Observational study Follow up: n.s.	Age, comorbidities, number of peritonitis episodes, PD modality, albumin levels, urine volume	Single centre; Patients on peritoneal dialysis n= 50 Age: 71.8 ±4.9	Mean survival time : 38.9±4.3 months; Survival rates at 1, 2, 3, and 4 years : 78.8%, 66.8%, 50.9% and 19.5% aHR: Age: 0.75, comorbidities 8.33, peritonitis 0.24, low albumin 0.17, pre-treatment urine volume 1.0; CAPD: 2.86 None of the factors studied predicted technique survival
Schroeder, 2017 (122)	Prognosis: 5-year risk of progression to RRT	Clinical research	Retrospective cohort study Follow up: 5 years	Predictive model: (8 variables including: Age, gender, eGFR, haemoglobin, proteinuria, systolic BP, antihypertensive medication use and diabetes.)	Health organisation members with CKD 3 and 4; followed for risk of progression n= 39013 (IC: 22,460; VC:16,553) Age: 74.6±10.1	GFR was the strongest predictor of progression to RRT RRT in 5 years: IC C-statistic: 0.96, R^2: 79.7; VC 0.95, R^2: 81.2
Schwenger, 2006 (346)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: 88.5 weeks	Time of referral (less than eight weeks before the start of dialysis)	Single centre; All patients starting dialysis between 1998 and 2001, comparison between <75 vs >75 n= 254 (58 were >75) Age: 79.6±4.3 (and 58.1±12.3 in those <75)	47% of all patients had later referral. More elderly had late referral (60% vs 43%); catheter start (69 % vs 46%). No difference of survival History of MI, late referral and start of dialysis through a fistula influenced prognosis

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Seow 2013 (347)	Prognosis: Changes in quality of life	Clinical research	Prospective Observational study Follow up: 24 months QOL tested at intervals over the study	Modality (CM vs RRT)	Single centre; Comparison of change in health-related quality of life between CM and RRT in elderly (>75) patients with ESRD (eGFR 8 - 12), who were sick (CCI>8) n= 101 Age:>75 (CM: 78; RRT: 71)	RRT did not improve kidney-specific symptoms or significantly improve QOL domains compared to CM PCS, MCS stable in CM group; no significant difference from RRT group. RRT group: improved cognition function scale, but worse scores on effective kidney disease and burden of kidney disease scale.
Shum, 2014 (138)	Prognosis: Survival; hospitalisation	Clinical research	Clinical, laboratory, sociodemographic Details on comparisons between conservative care and peritoneal dialysis	Comorbidities, ADL impairment modality (CM vs RRT)	Single centre; Adults ≥ 65; eGFR ≤15; followed for at least 1.5 years from first dialysis assessment visit; retrospectively chosen from the period 2003- 2010; n=199 (CM 42 ; PD 157) Age: CM 75.3± 5.7; PD: 73.4± 5.3	Hospitalisation rates: lower rates and days with PD; no significant increased risk of institutionalisation Mortality: CM: 92.9%; PD 61.1% Predictors of mortality in PD: Age, comorbidities, ADL impairment and emergency dialysis Survival advantage for PD persisted after adjustment for age and comorbidities.
Smith, 2003 (67)	Prognosis: Survival	Clinical research	Prospective Observational study Follow up: 3 to 57 months	Choice of treatment (initial choice, eventual treatment), functional status, comorbidities	All pre-dialysis patients presenting for assessment/counselling regarding RRT options in a renal clinic, classified into two groups	RRT: 186 started treatment; rest died or chose CM; CM: 11 switched to RRT Survival: Recommended CM: 6.3 vs 8.3 months if switched to RRT (not statistically significant) Cox PH: no survival benefit of RRT in

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					based on recommended therapy-CM or RRT; eventual treatment choice and outcomes studied n= 321 (recommended: CM – 63; RRT – 258) Age: 61.5 ± 15.4 (recommended: CM – 71 ± 12; RRT – 59 ± 15)	those recommended for CM, regardless of eventual choice Likelihood of CM recommendation: Older, sicker, diabetic, more functionally impaired, less likely to survive one year In those older, more functionally impaired, more comorbidities and diabetes, who are recommended for CM, no survival benefit from RRT
Sood, 2014 (348)	Prognosis: Mortality(renal transplant as competing outcome)	Clinical research	Retrospective Observational study Follow up: >10 years	Age, gender	Registry data; All adult patients starting dialysis between 2001 and 2009;41% women n= 28,971 All ages; compared by age groups	In both unadjusted and adjusted models, mortality for women was similar to men (HR 0.99 95% CI 0.96-1.03) however it varied by age groups. Women less than 45 at a greater risk of death than men. This persisted even when adding the competing risk of transplantation.
Stack, 2013 (349)	Prognosis: 1-year mortality	Clinical research	Retrospective Observational study Follow up: 1 year BMI changes charted by recording BMI at 3 and 6 months before HD start	Weight change before dialysis	Registry data to link patients in nursing homes that are on dialysis n= 11090 Age: 73	3.3% underweight; 36.5% obese. Median percentage change in body weight was -6%. Weight loss > 15% - aRR of mortality: 1.35; Weight gain > 4% - aRR: 1.24

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Sugaya, 2007 (350)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: n.s.	Bedridden (unable to sit up in bed without assistance)	Multicentre; All patients started on dialysis at a Japanese hospital between 1999 and 2003 ; Patients classified into different strata by age n= 219 (Bedridden: 76; Others: 143) Age: Bedridden: 70±13; Others: 64 ±14	Bedridden: usually due to cerebrovascular disease; more diabetics Median 50% survival time after start of HD: 56 months vs 120 months(overall population) Survival rates were lower in bedridden patients only in those < 50, not other age groups. Bedridden: no influence on survival in this Japanese population
Suzuki, 2010 (351)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 5 years	Ejection fraction on Echo; albumin	Single centre; all > 75 on PD; Divided into two groups by echo: EF <50% and >50% n= 46 Age: >75	Low EF: no effect at 1-year but reduces survival at ≥ 24 months; similar effects for S.albumin No difference incidence of peritonitis
Tangri, 2011 (84)	Prognosis: 1-, 3-, and 5-year risk of kidney failure	Clinical research	Prospective Observational study Follow up: Up to 5 years	Kidney Failure Risk Equation (KFRE); Best model contains age, sex, GFR, albuminuria, calcium, phosphate, bicarbonate and albumin)	Multicentre; Patients with predialysis CKD in two Canadian populations n= 3449 in IC; 4942 in VC Age 70± 14 in IC; 69± 14 in VC	Among the various models, the 8 variable model performed best. ESRD risk: c stat: IC: : 0.917 (0.901-0.933) VC: 0.841 (0.825-0.857) Also tested for other estimates of accuracy.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Taveras, 2012 (352)	Prognosis: Mortality, quality of life	Clinical research	Retrospective Observational study; Outcomes assessed through chart review Follow up: Up to 22 years	Observational / descriptive study	Single centre; All patients over 75 who started PD in a period of 22 years compared to younger n= 235 Age: >75	Higher mortality rates; similar peritonitis rates global quality of life and depression scores similar physical component scores lower than younger mental component scores better Older patients had reasonably good experiences on peritoneal dialysis with regards to quality of life and treatment complications
Thamer, 2015 (128)	Prognosis: 3- and 6-month all-cause mortality	Clinical research	Retrospective cohort study Follow up: 6 months	A simple score and a comprehensive score, consisting of: age, and women, ADL, nursing home residence, comorbidities, hospitalisation	US Renal Data System and claims data from the Centers for Medicare & Medicaid Services for older ESRD patients who initiated dialysis therapy in 2009–2010. n= 69,441 Age: >67	Simple score: AUROC = 0.69 in the validation sample. Comprehensive score AUROC = 0.72, high concordance between predicted vs observed risk. Mortality probabilities were estimated from these models
Thong, 2008 (353)	Prognosis: Mortality	Clinical research	Prospective Observational study Follow up: 2.7 years	Self-rated health question, and Clinical, laboratory, sociodemographic variables	Multicentre; Patients on HD n= 1443; 31% were > 65 Age: 59.7±14.8	Self-rated health is an independent predictor of mortality in all age groups, even after controlling for demographic and clinical confounders. Adjusted HR 10.58 for older patients with poor self-rated health

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Thorsteinsdottir, 2013 (354)	Prognosis; Quality of evidence	Review	Applied GRADE framework to evidence on hemodialysis in very elderly patients	Quality of evidence for benefit; for harm; summary of qualitative analysis	Databases from January 2002 to August 2012 searched for systematic reviews of clinical and economic outcomes of HD in the elderly	Quality of evidence for benefit (USRDS): Expected remaining lifetime for patients: 75-79 : 2.8 years 80-84 : 2.3 years >85 years old: 1.9 years; Modest survival benefit in elderly, low quality evidence. Quality of evidence for Harm: - Single cohort studies - poor functional outcomes in nursing home residents Qualitative: On HD: Aggressive end-of-life care; deaths in hospital; lack of choice; regret. 2 studies: QOL similar or equal in CM versus HD
Tsai, 2016 (355)	Prognosis: All-cause mortality	Clinical research	Prospective Observational Study; Follow up: 54 months	Geriatric nutritional risk index (GNRI)	Single centre; Patients older than 65 on HD; Patients divided into two groups with GNRI value n= 104Age: 72 ± 6	aHR: GNRI > 92 - 0.41 Risk of death for each one-unit increment: aHR: 0.91 (with confidence intervals)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Tuğcu, 2018 (356)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: 19.7 (11) months	Comorbidity score(Liu), age, performance status (ECOG)	Single centre; Patient starting dialysis from 2009 to 2014 over the age of 65; Patients switching to PD or transplant were excluded. n= 99 Age: 75±7	Odds ratio: Age 5.5, Liu comorbidity score 4.94,ECOG-PS 3.98 (all with confidence intervals)
Verberne, 2016 (140)	Prognosis: Survival	Clinical research	Retrospective Observational study Follow up: n.s.	Mode of treatment-CM or RRT	Single centre; All patients ≥ 70 receiving renal care; eGFR <20. Survival calculated from time of decision regarding RRT/CM. n= 311 (CM 107, RRT 204). Age: CM 82.5± 4.5; RRT 75.9± 4.4	Survival: less with CM (0.5 vs 2.8 years at eGFR<10; 1.5 vs 3.1 years at eGFR<15) Survival in those over 80: no statistically significant advantage (1.4 Vs 2.1 years, p 0.08) Survival in those with high comorbidity: benefit of RRT significantly reduced (1 vs 1.8 years, CM vs RRT) In those > 80, no significant survival advantage for RRT over CM.
Verdalles, 2010 (357)	Prognosis: Mortality	Clinical research	Prospective Observational study Follow up: 3.3 ± 2.2 years	Charlson comorbidity index, Comorbidities	Single centre; Patients > 75 starting dialysis since 2000 n= 139 Age: 78.6 ± 2.6	In the univariate model, the factors associated with mortality were diabetes, chronic obstructive pulmonary disease, heart failure and the Charlson index. In the multivariate model, only the Charlson index remained as an independent

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						predictive factor (p = 0.006).
Villain, 2015 (358)	Prognosis: Survival	Clinical research	Prospective Observational study Follow up: 2.1 (1.2, 3.4) years BMI variation is modelled by individual linear regression models leading to a baseline level and a slope coefficient for each patient - compared to survival	BMI changes over time	Registry data; elderly haemodialysis patients. n= 502 Age: 80.9 ± 4.2	Mean BMI change was -1.1% per year. Each point lower baseline BMI : 4% increase in the risk of death (aHR 1 .04) Greater than 5% loss and gain were both associated with poor survival after adjustment when compared to normal BMI with no significant change. annual 5% decrease of BMI: aHR 1.5 obesity - longer survival
Villain, 2016 (359)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 2.1 years	Serum albumin-baseline value and rate of change	Registry data; Elderly adults on haemodialysis n= 463 Age:80.9 ± 4.3	41% mortality rate overall. Main baseline serum albumin 3.63 (0.77). Mean annual rate of change -0.04 (0.53) Both baseline value and rate of change associated with mortality; Compared to albumin > 3.8 and no significant rate of change, both low and high rates of change had poorer outcomes (particularly < 3.2 g/L)

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Vrtovsnik, 2002 (360)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: n.s.	Comorbidities, age	Single centre; Patients on dialysis from 1982-1989, Age over 75 n= 292 Age: 81.5 (75-92)	Worse survival with worsening CCI score - Survival inversely correlated with Charlson comorbidity index 1-year survival- 80%, 2 years 45%, 5 years 7%.
Wagner, 2011 (124)	Prognosis: Mortality (in those who continued HD beyond 3 months)	Clinical Research	Prospective Observational study Follow up: At least 3 years	Predictive model (variables including age, demographics, comorbidities, primary kidney disease, treatment modality and biochemistry)	UK Registry; adults >18 incident to dialysis in the period 2002-2004 IC (Random split; two thirds of the original cohort): n= 3631; Age: 64 (49-73) VC: n= 1816; Age: 64 (51-74)	C-stat: IC: 0. 0.74; VC 0.73 Both with good calibration. Model accurately classified patients with low (6%), intermediate (19%), high (33%), and very high (59%) mortality risk.
Wick, 2016 (121)	Prognosis: All-cause 6-month mortality	Clinical research	19- point risk score, narrowed to 7. Follow up: 6 months	Predictive model (7 variables, including: Age>80, eGFR, comorbidities, hospitalisation.)	Single centre; Administrative and clinical data; only derivation cohort n= 2199 Age: >65	C stat 0.72; Good calibration
Wong, 2007(361)	Prognosis: One-year survival	Clinical research	Prospective Observational study Follow up: 1 year	Stoke comorbidity index, age, GFR, haemoglobin, calcium and phosphate	Single centre; Patients in a multidisciplinary clinic for renal supportive care n= 73	At one year, the survival for comorbidity grade 0, 1 and 2 were 83%, 70% and 56 respectively. other prognostic factors included age, GFR, haemoglobin,

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					Age:79(40-93)	calcium and phosphate
Wong, 2014 (362)	Prognosis: Survival, hospitalisation, subsequent intensive procedures, dialysis discontinuation	Clinical research	Retrospective Observational study Follow up: n.s.	Hospitalisation for more than two weeks and receiving at least one intensive procedure the beginning of dialysis	Registry analysis; Medicare beneficiaries starting dialysis between 1995 and 2008 n= 416,657 Age:>67	64.5 initiated dialysis in the hospital; 36.6 hospitalised for more than two weeks; 7.4% who underwent one or more intensive procedures compared to outpatient initiation, those with high intensity had a shorter median survival, more hospitalisation, more subsequent intensive procedures and less likely to have discontinued dialysis before death. Highest to lowest level of intensity of care at initiation: adjusted HR 1.44 (1.42-1.47)
Wu, 2018 (363)	Prognosis: Mortality; Cardiovascular mortality	Clinical research	Retrospective Observational study Follow up: 23.4 (4-60) months Kaplan-Meier, log rank test, Cox proportional hazards, Schonfield residuals	Testosterone level, Skeletal muscle mass index (SMMI)	Single centre; Patients on HD n= 137 Age: 72	Testosterone level was associated with skeletal muscle mass index Outcome worse for low testosterone level, except when adjusted for SMMI. Both had equally predictive value for mortality. Overall mortality C stat: testosterone 0.812, skeletal muscle mass index 0.855, with confidence intervals

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Yang, 2007 (364)	Prognosis: Patient survival, technique survival	Clinical research	Retrospective Observational study Follow up: n.s.	Cholesterol, albumin, calcium	Single centre; all peritoneal dialysis patients n= 358 (145 over 65 years old) Age: All ages	Survival of elderly patients were shorter than that of younger patients. Technique survival was no different between older and younger groups. aHR mortality (initial values) : Albumin 0.95, S Calcium 5.19; cholesterol 0.74
Yang, 2014 (365)	Prognosis: Mortality(monthly mortality rates)	Clinical research	Retrospective Observational study Follow up: n.s.	Periods of mortality; descriptive study	Multicentre; All patients treated by a dialysis provider in nursing homes; included all forms of HD, PD (and even daily HD) n= 3926 Age: 67 (18-100)	Incident mortality rates were highest in the three months after starting dialysis. Subsequent mortality rates showed improvement. Incident first month annualised mortality rate of 70%
Yazawa, 2016 (366)	Prognosis: 3-month mortality	Clinical research	Prospective Observational study Follow up: 3 months	Functional status; age	Registry data; all patients starting dialysis in Japan in 2007 who had data about functional status	In overall data, 3-mo mortality is relatively common among elderly patients (over 80, 15.8% vs 7.1% overall) Functional status worsened outcomes, especially true in the elderly; Severe functional impairment: aRR–3.93; moderate aHR–2.38
Zhang, 2014 (367)	Prognosis: Mortality	Clinical research	Retrospective Observational study Follow up: 3 years	Access type at initiation of HD	Registry data; All adult HD patients on the Canadian Organ Replacement Register in	"In Canada, use of an AV-access is associated with lower mortality across all age categories, even in the very elderly"

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					2001–2010; stratified by age groups n= 39721 Age: 58% were > 65	(All patients were on organ replacement register) aHR for AVF use , effect on mortality 0.73 - 0.77 in all groups > 65 years old
Balogun, 2017 (48)	Influence on quality of life	Review	Systematic review	QOL, perceptions and health satisfaction of older adults (>65) on RRT	23 studies met criteria for selection.	Of these, 47%: overall health-related and mental component summary QOL scores in elderly a similar to or higher than those of age-matched controls or younger , although the physical component summary QOL scores tended to be lower in older adults. Studies on health perception or satisfaction in older adults and low in number
Braga, 2011 (187)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: KDQOL-SF; MOS SF 36; Clinical, laboratory, socio-demographic variables also considered.	Factors associated with health-related quality of life in elderly on dialysis;	Multicentre Brazilian study; 12 units; part of a larger study of elderly on haemodialysis n= 223 Age: >60	Multivariate analysis of factors affecting: PCS: older age, female gender, history of hospital admissions; three or more self-reported chronic diseases MCS: three or more chronic diseases; long duration of treatment Overall, lowest scores were for burden of kidney disease; work status and patient satisfaction; physical functioning, role-physical and overall health

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Brown, 2012 (183)	Influence on quality of life	Opinion	Opinion paper	Improving QOL in elderly dialysis patients		Dialysis has multiple impacts of lifestyle - therefore, choose carefully. Need to change the focus of care to quality of patient's life, rather than dialysis as default Several advantages and disadvantages of attending a specialist renal clinic
Ch'ng, 2015 (146)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Euro-QOL EQ 5D; Geriatric depression score (GDS)	Comparison of quality of life between dialysis and non-dialysis treatments	Single centre; 100 on dialysis, 100 on non-dialysis treatment n= 200; Age: >65	QOL : Overall QOL Worse in dialysis compared to non-dialysis in this brief study Each 5D index score significantly lower in dialysis population older adults more likely to be depressed
De Pasquale, 2012 (147)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Symptom checklist revised-90; SF 36	Correlation between psychological symptoms and quality of life, in relation to age/vintage/education	Single centre; Patients on haemodialysis n= 20 Age: >55	QOL: Affected by age,somatization, dialysis vintage and education Number of symptoms increased with age Somatization (a global score) - affected mental health vitality and pain More time on dialysis worsened positive symptom distress and obsessive behaviour; Higher the educational level, the more the negative perception of health
Feng, 2013 (368)	Influence on quality of life; Lived experience;	Clinical Research	Prospective Observational Study Surveys used: Geriatric	Prevalence of depressive symptoms, their	Study data; Singapore longitudinal ageing study cohort	Low MCS score: depression Depression in 13%, led to 30% lower MCS scores

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
	Prognosis: Mortality		depression Scale; SF-12 quality of life; Mortality at four years	impact on mortality and quality of life, and correlates of depressive symptoms;	consisting of patients with CKD 3 and 4. (%age of those with CKD 4 not mentioned.) n= 362 Age: Depressed(n= 42): 71.6 ±7.9; Not depressed: 70.1 ±7.8	Correlates of depression: ADL impairment, Number of comorbidities, housing status Depression associated with mortality only in unadjusted analysis
Germin-Petrovic, 2011 (369)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: SF 36; compared with general population Also Clinical, laboratory, socio-demographic variables	To compare the QOL of chronic HD patients with general population and to analyse influencing sociodemographic and clinical factors	Multicentre; Prevalent HD patients n= 255(Compared with 132 from general population) Age: 65.1±12.5	Better HRQoL : patients <65 years old, males, patients with higher educational level and HD vintage < 1 year. PCS and MCS: Age (>65 vs <65) only influencing factor
Giglio, 2018 (370)	Influence on quality of life; Lived experience; Prognosis: Mortality	Clinical Research	Prospective Observational Study Surveys used: KDQOL- SF; 7point-SGA Other measures: Anthropometric measurements, handgrip strength and a validated prediction equation for appendicular	Effects of sarcopenia on nutritional status, poor quality of life (QoL), hospitalization and mortality	Multicentre; elderly patients on HD treated in 6 dialysis facilities in Brazil. n= 170; Age: 70.6 ± 7.2	Reduced muscle mass was observed in 64% of the patients, reduced muscle strength in 52%, and Sarcopenia in 37%; Low muscle strength was associated with worse QoL domains. In multivariate adjusted analyses low muscle strength, sarcopenia associated with higher hospitalization, and sarcopenia with mortality

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			skeletal muscle mass Follow up: Median 17.5 months			
Griva, 2014 (371)	Influence on quality of life	Clinical Research	Cross-Sectional Study; survey-based. Surveys used: KDQOL-SF, HADS-SF, WHOQOL-SF	To compare Quality of Life, anxiety and depression between older ≥65 years) and younger (< 65 years) patients across APD and CAPD	Single centre; patients selected from PD Centre. n= 201 (>65 - 74; <65 - 127) Age: >65 versus <65	Quality of life outcomes were lower than the general population Older patients : higher satisfaction with care, less effects of kidney disease better overall QOL No difference in QOL between the APD and CAPD
Iyasere, 2014 (372)	Influence on quality of life	Review	Narrative review	Quality of life in advanced disease and the need to Screen for QOL		MCS: Cognitive impairment is a risk factor for mortality and morbidity; Depression is common; risk factors: increasing comorbidities, longer dialysis vintage; female gender, white race PCS and physical function: lower kidney function; reduced skeletal muscle mass, vitamin D deficiency, albumin, comorbid cardiac/lung diseases correlate
Johansson, 2012 (373)	Influence on quality of life	Thesis	Cross-Sectional Study of QOL Outcomes Qualitative analysis of	Whether PD is under-utilised by older	Multicentre; Patients on both forms of dialysis. n= 140 (HD 70; PD 70)	PD : less illness and treatment intrusion than those on HD, other QOL outcomes similar.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			decision making QOL assessments included the SF-12 and Illness Intrusiveness Ratings Scale	people in the UK; QOL and the modality decision-making process.	Age: 73	52% Involved in their modality decision; 33% desire greater involvement Decisions are influenced by : patients' prior experiences, medical and social context; Quality of education (latter affects also integration of dialysis into patients' lives).
Kanamori, 2011 (374)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: QOL by Visual analogue scale on 10 questions; compared to those in community	Comparison of the psychosocial QOL of elderly HD patients with that of healthy elderly	Single centre; Elders on HD compared to elders in the community n= 83 Age: >65	Older dialysis patients: lower scores in mood, sleep, happiness Parallel scores in family relationships and friendships Dialysis vintage had effects on: sleep, memory, family relationships. Sleep affected by: friendships, economic status, trouble with access
Kesikburun, 2017 (148)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Surveys used: Nottingham Health Profile; Beck Depression scale Clinical, laboratory, socio-demographic variables	Identify clinical and demographic determinants of health-related quality of life in elderly haemodialysis patients	Single centre; Patients on HD divided into more and less than 60 years old n= 39 Age: 71±8	QOL influenced by: Beck depression item scores had a major effect; also haemoglobin, albumin, phosphate, number of comorbidities, being married (Abstract only - full text not located}
Kitagawa, 2017 (375)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: SF 12 questions (selected)	Effects of dialysis session length on quality of life	Study data; J-DOPPS; Patients over 65; grouped into short	QOL : Large study, no adverse effect on QOL from session length (although mortality is improved with longer length)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					medium and long sessions n= 1187 Age: >65	
Kittiskulnam, 2016 (63)	Influence on quality of life	Review	Literature review	Physical functioning and frailty; cognitive function; emotional health, including depression and anxiety; and health-related quality of life.	Some elderly, but predominantly all patients with CKD, and at varying stages	Worsens QOL: emotional problems Improves QOL: treatment of anaemia, exercise, personalised alterations in dialysis regimes
Kutner, 2000 (376)	Influence on quality of life; Lived experience	Clinical Research	Cross-Sectional Study; Qualitative research; used interviews; Self-assessed disease symptoms and/or side effects of treatment, disability days, and health satisfaction	Association of race with disease symptoms, health satisfaction in older adults on dialysis	Multicentre; patients on haemodialysis. n= 305 (183 black, 125 white) Age: >60	Race affects self-perception of QOL and symptoms Older Whites, compared to older Blacks, were at increased risk for reporting nausea, sexual dysfunction, recent bed disability days, fatigue, greater HD recovery time, and health dissatisfaction
Laegreid, 2014 (52)	Influence on quality of life	Clinical Research	Cross-Sectional Study; survey-based Surveys used: SF-36, subjective global assessment (from which physical function is calculated)	The impact of nutritional status, physical function, comorbidity and early versus late start in dialysis on QOL in older	Multicentre registry data; Patients on dialysis in the Norwegian renal registry n= 233 Age: >75	Better QOL (all scales): better scores in physical function No effect on QOL: early vs late start, PD vs HD, nutritional status or comorbidities;

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
				dialysis patients		
Laudański, 2013 (377)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Situation and Trait Anxiety Inventory, the Profile of Mood States, the Cognitive Stress Appraisal Questionnaire, and the Nottingham Health Profile	Compare strategies older and younger patients on dialysis used in coping; therefore, compare quality of life	Single centre; patients on dialysis n= 109 patients, 89 volunteers Age: mean 69	QOL: No significant differences when using the Nottingham profile (outputs are mainly psych than physical for this scale) despite differing threat perceptions and coping styles
Loos, 2003 (378)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Surveys used: SF 36 Clinical, laboratory, socio-demographic variables	Effects of ESRD on QOL; compare renal and other diseases	Single centre; patients with end-stage renal disease prior to dialysis. n= 169 patients, 169 controls Age: ≥70	ESRD had lower scores in dimensions of physical function, role limitation and vitality. After adjustment, no difference in quality of life if dialysis was planned, when compared to non-ESRD population Unplanned dialysis: lowest quality of life; especially physical function (mainly due to pulmonary oedema)
Martins, 2013 (88)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: KDQOL - SF	Effect of age on quality of life	Single centre; patients on HD n= 74 (those >60) Age: >60	QOL: Age may affect the components of quality of life that are affected by dialysis. Older people have diminished scores on: physical functioning, general health, energy/fatigue, security burden,

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						professional role, sexual function
Moura, 2015 (379)	Influence on quality of life	Clinical Research	Cross-Sectional Study; survey-based. QOL: Using KDQOL-SF	Effect of ageing on perception of health-related quality of life, dialysis adequacy, haematological, iron status, inflammatory and nutritional markers.	Multicentre; Patients on hemodiafiltration in Portugal n= 305 Age: All ages, classified by quartiles of increasing age	> 57 years - worse in QOL domains of: Effects of kidney disease, work status, physical functioning, role–physical Older male patients: Significantly higher values on symptoms/problem list, pain and quality of social interactions.
Mucsi , 2008 (188)	Influence on quality of life	Opinion	Opinion paper	Interactions between comorbidities and quality of life		Comorbidity scores explained < 20% of physical component and < 5% of mental component Definitions of comorbidity vary. Effect of comorbidity on quality of life is separate from effect on survival since there is a subjective component
Nitsch, 2011 (380)	Influence on quality of life	Clinical Research	Qualitative analysis Interviews by study nurses using standardised protocol derived from tools to measure sickness	Interaction between reduced kidney function and quality of life in older people	Older adults with GFR less than 45; Part of Medical Research Council (MRC) Trial of the Assessment and Management	Lower QOL: lower GFR; previous stroke or myocardial infarction; diabetics; previous manual occupations; living alone (poorer morale and social interactions scores when living alone)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			impact, morale; creatinine measurements for GFR		of Older People in the Community. n= 2962 Age: >75	
Pilger, 2017 (381)	Influence on quality of life	Clinical Research	Clinical, laboratory, sociodemographic, Spiritual well-being scale, WHO QOL-BREF; WHO-OLD	analyse the relationship between spiritual well-being, sociodemographic, economic, religious, and health variables and the quality of life of older adults undergoing hemodialysis.	Multicentre; Patients undergoing HD n= 169 Age: >60	QOL : improved by spiritual, religious and existential well-bring scores (in the physical, psychological, social relationships, and environmental domains)
Saito, 2016 (382)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: EQ 5D 5L; Visual analogue scale	Factors affecting quality of life in elderly Japanese cohort	Single centre; patients on HD n= 216 Age: mean 67.9	QOL affected by: Age; Duration of dialysis Health utilities scores differed according to age groups; dropping in the groups above 70 Japanese elderly had better health utility scores than other countries
Schmidt, 2012 (103)	Influence on quality of life; Lived experience	Opinion	Opinion paper	Unique needs and characteristics of the older population with ESRD	High symptom burden, depression, comorbidities - lead to poorer QOL in elders. Clinically important outcomes are relative; older	

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					patients have different parameters. - Progression Vs death is an important consideration - Burdens / QOL risk exists with dialysis in the elderly	
Sclauzero, 2013 (383)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based & quantitative analysis Surveys used: SF 36; activities of daily living; instrumental activities of daily living; Karnofsky; SGA; Clinical, laboratory, socio-demographic variables	Effect of components of frailty (disability, dependence, nutritional status, comorbidities, poor social conditions) on the QoL of patients on dialysis.	Multicentre; Patients on dialysis; n= 203 (190 on HD) Age: all ages; mean 72.	QOL : Affected by components of frailty Improved by : living with family, economic condition, widespread social relationships; Worsened by: Impaired nutritional status, disability, dependence, comorbidities
Seckinger, 2016 (169)	Influence on quality of life; Lived experience	Clinical Research	Prospective Observational Study; Survey-based Surveys used: 47-item Functional Assessment of Chronic Illness Therapy – Anaemia score (FACT-An,v 4) 24 months of follow up data	Morbidity, mortality and quality of life (QoL) in those >75 were examined and compared with a younger cohort.	Study data; part of ELDERLY study; All receiving Aranesp, comparisons between >75 and <75 n= 796 Age: those over 75 compared with others	Physical, functional status in older: lower; more decline Social well-being in older: less pronounced decline; finally equalised with younger population. Hospitalisation rate in older: only slightly higher.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Sugisawa, 2016 (384)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based and quantitative Surveys used: CES-D scale for depression; Clinical, laboratory, socio-demographic variables; household income	Changes in physical and mental health gaps with age, period, and cohort for patients undergoing hemodialysis	Registry data; patients on haemodialysis n= 32,209 Age: all ages (50% of patients were over the age of 60)	QOL: Affected by socio-economic status; affected by birth cohort; affected by age. Older patients, the lower SES: less complications
Tattersall, 2005 (385)	Influence on quality of life; Lived experience	Opinion	Opinion paper	Unique needs of those >80 on dialysis.		Psychosocial domains similar between older and younger patients; physical domains poorer. Overall healthcare costs are higher. Predictors of poor survival: advanced age, high comorbidity, high dependency
Turkmen, 2012 (386)	Influence on quality of life; Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Modified post-sleep inventory, MOS SF36; Beck depression inventory	Relationship between sleep quality, depression, and health related QOL in elderly	Multicentre; Subgroup of larger study; Patients on HD n= 63 Age: 70.5 ± 4.7	Lower PCS: common in poor sleepers Sleep affected by: depression score, mental component score and age Overall: poor sleep in 71%; depression in 25% Poor sleepers : more depression, diabetes, lower PCS
Unruh, 2008 (144)	Influence on quality of life; Lived experience	Clinical Research	Prospective Observational Study; Survey-based Surveys used: Index of well-being; KDQOL - LF, MOS SF	Change in QOL, experience of HD over three years	Study data; Patients on HD in the HEMO study; Secondary analysis. n= 1813 (391 were >70)	Older patients: better overall global quality of life; better patient satisfaction; lower symptom and problems scores; worse sleep and significantly

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			36 completed every year		Age: 57.6 overall; 74.4 in those >70	worsening cognitive function; Only minor declines in physical or mental scores over a three-year period in those over 70 in those who survived; no major differences to younger patients.
van Doorn, 2004 (387)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Katz ADL scale; IADL; MMSE; Short depression scale; KDQOL; SF 36	Functional state, mental state and QOL in elderly HD patients.	Single centre; patients on HD n= 82 (those >60: 67) Age: All ages; median 70.5	QOL negatively correlated with activities of daily living score and instrumental activities of daily living score No differences in mean quality-of-life scores for all the four groups.
Voskamp, 2018 (23)	Influence on quality of life	Clinical Research	Cross-Sectional Study; Surveys used: Dialysis symptoms index; RAND-36; Also Clinical, laboratory, socio-demographic variables	Effect of symptoms on QOL in pre-dialysis patients	Study data (EQUAL study) advanced CKD patients in 6 European countries n= 1079 Age: >65	Symptom number and symptom severity affected both MCS and PCS Changing symptom number and severity relates to changes in quality of life Symptom number and severity, demographics and clinical variables affect QOL PCS: contribution of symptoms is smaller. Women had more number and severity of symptoms and a lower quality of life.
Aasen, 2012 (150)	Lived experience	Clinical Research	Qualitative research; analysis of interviews	Explore how elderly patients on HD perceive	Single centre; patients on HD; n= 11 Age: 72 – 90	Elderly patients can feel disempowered; they feel dominated and not part of decisions. Healthcare

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
				patient participation.		professionals seem to have all the power. 1. The healthcare team's power and dominance (feeling like being in prison; healthcare teams' knowledge; patients trust in fear; threatened identities) 2. Struggle vision for shared decision-making (blood access; dry weight; diet; the time of treatment
Abdel-Rahman, 2011 (388)	Lived experience	Clinical Research	Prospective Observational Study: falls, all-cause death, nursing home admission, the number and duration of all hospitalizations	Risk factors and the outcomes of falls in HD patients	Single centre; HD patients n= 76 Ages : all ages	Falls are common in HD patients, with a higher incidence in females and elderly, and are associated with worse outcomes, more so in recurrent fallers.
Abdel-Rahman, 2011 (389)	Lived experience	Review	Narrative review			Inadequate information regarding falls in elderly dialysis patients. Reasons for falls - related to aging, to ESRD/HD; to CKD comorbidities. Falls can have several complications. Important to assess the risk of falls
Abdelrahman, 2014 (390)	Lived experience	Clinical Research	Cross-Sectional Study; Surveys used: CGA Clinical, laboratory, socio-demographic variables	To assess the prevalence of cognitive impairment and the association of different	Single centre; patients on HD; n= 94 Age: >60	Ex: Cognitive impairment is common in Egyptian older adults on HD More in those with older age, low education, lower level of serum sodium, longer dialysis

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				patients' demographics and characteristics with cognitive impairment.		vintage and higher dry weight.
Axelsson, 2012 (175)	Lived experience	Clinical Research	Qualitative research - Content analysis of interviews; qualitative descriptive design with an inductive approach	Thoughts and feelings relating to death and dying when living with haemodialysis approaching end of life.	Single centre; HD patients; 31 interviews n= 8 Age: 66-87	Being aware that death may be near Adapting to approaching death Being alone with existential thoughts
Birmele, 2004 (391)	Lived experience	Clinical Research	Retrospective Observational study Doctor and nurse completed questionnaire from medical records and notes; Clinical, laboratory, socio-demographic variables	Cause of death, medical and social characteristics of those who withdrew from HD	Single centre; French HD population n= 40 Age: 65 – 89	20% of all deaths 29% of all >80 Those withdrawing: more dementia; poor general condition; dependent for everyday activities No effect of age, gender, other Variables.
Bowling, 2014 (392)	Lived experience	Clinical Research	Prospective Observational Study Surveys used: Medical history questionnaire; MMSE, GDS; Life-Space Assessment Questionnaire.	association of reduced eGFR with longitudinal life-space mobility trajectory among community dwelling	Study data; Community dwelling older adults in the University of Alabama at Birmingham (UAB) Study of Aging. n= 390 Age: >65	Low eGFR <45 was associated with a trend toward a more rapid decline in life space mobility among community-dwelling older adults compared to those with higher eGFR

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			Clinical, laboratory, socio-demographic variables Follow up: 4.5 years	older adults		
Bowling, 2017 (159)	Lived experience	Clinical Research	Qualitative analysis; Six focus groups were conducted	Challenges older adults face maintaining CKD self-management regimens.	Single centre; patients on HD; n= 30 Age: >70	1. Complexity : multiple medical conditions, complex regimen of recommendations, sometimes discordant. 2. Prioritisation is a strategy for managing complexity
Brennan, 2015 (393)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: POS-Renal	Symptoms in patients being managed conservatively	Single centre; stage 5 CKD being managed conservatively in a renal supportive care clinic n= 42 Age: mean 83	Multiple symptoms. Many of those symptoms are moderate to overwhelming in severity and not easily predicted on the basis of the eGFR or haemoglobin.
Bristowe, 2015 (164)	Lived experience Information needs	Clinical Research	Qualitative analysis of interviews	Need for early Advance Care Planning for people on HD	Multicentre; Purposive sampling of patients at 2 dialysis centres for age, vintage, symptoms. n= 20 Age: Mean 62; 9 over 65; >65 compared to <65	Close and supportive relationships with HCPs; Busy cultures of unit, lack of opportunity to speak to a doctor; Conveyor belt nature of HD, Difficulty of getting information; culture of silence about other patients, esp. when they die, Impact on day-to day life, loss of independence, enjoyment; impact on family and friends Acknowledgement the various themes around dialysis initiation (Fear, sadness, disbelief at commencing HD,

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						Struggle, Denial, Grief, Realisation) More detail around the lifestyle changes - mere booklets not enough; Greater involvement in decisions Impact on lifestyle Facing mortality and constant thoughts of death Talk about future care
Brown, 2008 (171)	Lived experience	Opinion	Opinion paper	PD for older people		- There are advantages to PD - no problems with access; no impact of cardiac disease; no transport. Older patients can be trained; may have others willing to help. - No statistically significant difference between PD and HD regarding survival or hospitalisation rates or quality of life in either of the North Thames dialysis study or the French REI in registry. - similar mental scores were obtained; lower physical scores than the general population - assisted PD in several countries - with community support, more patients will choose PD
Brown, 2010 (394)	Lived experience	Opinion	Opinion paper	Old age and frailty in the dialysis population		Older patients on dialysis: frailty, cognitive impairment, depression and

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						changes in body composition. Frailty as a measure of ageing. Biological and psychosocial age may be different from chronological age
Chiu, 2008 (395)	Lived experience	Clinical Research	Lighthouse Near Visual Acuity Test, Lea Screener contrast sensitivity test, Titmus Stereotest, Folstein Mini-Mental Status Examination.	Visual impairment in elderly patients receiving HD	Single centre; Patients on HD n= 159 Age: >65	Elderly HD patients have a high frequency of visual impairment (95.6% decreased visual acuity; 39% fulfil criteria for legal blindness)
Cook, 2006 (396)	Lived experience	Clinical Research	Prospective Observational Study Baseline evaluation; then visited by research nurse every 2 weeks till the completion of the study to assess if they had fallen Minimum follow-up of 1 year	Falls in the older HD population	Single centre; patients on HD n= 162 Age: >65	In the HD population, the fall risk is higher than in the general community 47% of patients had falls (fall-incidence 1.6 per person - year) Risk factors: age, comorbidity, mean predialysis systolic BP, and a Previous history of falls
Cook, 2008 (397)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: MMSE, TUG, Tandem stance, chair stands; ADL, IADL scales Also Clinical, laboratory, socio-	to characterize the proportion of patients with one or more disabilities in the four core ADL self-care tasks(bathi	Multicentre - all hospitals in a single Canadian Health Network; patients on HD: n= 162 Age: 74.8±5.9	Ex: Functional deficits very common; Risk for ADL dependency: low education, multiple prescriptions, poor timing in "up and go" physical performance

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			demographic variables	ng, dressing, transfers from bed to chair, and walking within the home) and to identify clinical variables that are associated with functional dependence.		
Cupisti, 2017 (398)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Rapid assessment of physical activity test, 30 second set to stand test, malnutrition-inflammation score.	physical activity, capacity and nutritional status in older peritoneal dialysis compared to CKD patients	Single centre; patients on PD compared to CKD; n= 71 patients on peritoneal dialysis; 80 patients with CKD stages 3 to 4 Age: >60	High prevalence of low- performance capacity and sedentarism Sedentary patients number double that of active patients reduce physical performance in both groups PD: association between STS and RAPA with malnutrition inflammation score.
de Guzman, 2009 (154)	Lived experience	Clinical Research	Qualitative analysis; Semi structured interview and checklist	Lived experience of the elderly undergoing haemodialysis; analysis of coping	Single centre; patients on HD; n= 13 Age: >60	Different strategies for how patients adopt to dialysis -coping as scaffolding; the power to hold on (clinging to something important) -coping as sailing: the power to let go; forgetting, overcoming -coping a sanguinity; the power to see the difference; to be

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						cheerful, optimistic, strong
Derrett, 2010 (160)	Lived experience	Clinical Research	Qualitative analysis: – Two methods of cross-Sectional data collection were used: (i) structured quantitative interviews with all participants; and (ii) qualitative interviews with a selected subgroup.	Satisfaction with home-based dialysis in older patients.	Single centre; Participants were either dialysing at home or training for dialysis at home. n= 45 Age: >60	Despite experiencing frustration with dialysis itself, expressed satisfaction across four categories: staff, information provision, involvement in decision-making and confidence in managing dialysis. Dissatisfaction was infrequent.
Desmet, 2005 (166)	Lived experience	Clinical Research	Prospective Observational Study Clinical, laboratory, socio-demographic variables, Tests of balance Falls, fractures recorded for 12 months follow-up	Falls in HD patients	Single centre; patients on HD n= 308 Age: median : 70.9 overall, 74.7 among those who fell	Falls are common.(12.7%; 1.184/patient-year); 3.9% experienced fall - related fracture Risk factors: older age (odds ratio, 1.057/y; P = 0.01), diabetes (odds ratio, 2.747; P = 0.02), high number of prescribed oral drugs (odds ratio, 1.19/drug; P = 0.011), antidepressant use (odds ratio, 5.263; P < 0.001), and failing to walk 10 m without help (odds ratio, 2.057; P = 0.001)
Dimkovic, 2008 (399)	Lived experience	Opinion	Opinion paper	Peritoneal dialysis in the elderly		Not very different with modality related complications. quality of life - often need assistance; peritoneal dialysis may have better life satisfaction: not

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						enough studies comparing quality-of-life in elders Hospitalisation supposed to be more according to the study (however, this has been disproved by recent papers)
Elliott, 2014 (181)	Lived Experience, Influence on quality of life	Clinical Research	Qualitative research; analysis of interviews Survey used for QOL: KDQOL- SF	The life experience and quality of life assessments of people living with dialysis	Single centre; Patients on HD & their family members n= 20 patients, 11 carers Age: 80.6 (70-100)	Duration on dialysis and physical losses change the perception of quality of life over time 1. The reason they were alive has changed; how they spent their time each day has changed 2. Patients described thriving; positive attitudes to help with this 3. Surviving: diminishing abilities; family support and not being a burden increasingly important 4. Surviving-moving to poor quality of life: progressive decline 5. End-stage - not meeting the quality of life standard; considerations of discontinuing dialysis
Etgen, 2009 (400)	Lived experience	Clinical Research	Prospective Observational Study Survey used: 6-Item Cognitive Impairment Test (6CIT).; Clinical, laboratory, socio-	Relationship between renal function and cognitive impairment	Study data; From Intervention Project on Cerebrovascular Diseases and Dementia in the Community of Ebersberg (INVADE);	Presence of CKD increases the chances you will develop cognitive impairment over the next 2 years moderate-to-severe impaired renal function is associated with incident cognitive impairment after 2 years in a large

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			demographic variables		pre-dialysis patients n= 3679 Age: >60	cohort of elderly subjects.
Findlay, 2016 (177)	Lived experience	Clinical Research	Retrospective Observational study Data extracted from registries (patient demographics and comorbidity, cause and location of death, duration of RRT and pertinent free text comments) from 1January 2008 to 31 December 2014 from a mortality report to the renal registry	Decisions to withdraw from dialysis in a national renal Registry	Registry data; Patients who had withdrawn from HD n= 497 Age: median 68	Factors important to physical independence — prior cerebrovascular disease and increasing age — are associated with withdrawal. Increasing age, female sex and prior cerebrovascular disease were associated with dialysis withdrawal Analysis of free text : image of physical and psychological decline accelerated by acute illnesses.
Foster, 2016 (401)	Lived experience	Clinical Research	Multicentre prospective study Survey used for cognition: MoCA (< 24 score identified as impairment)	Cognitive impairment in pre-dialysis CKD stages 4 and 5	Multicentre prospective study; Adults with CKD 4 and 5 not on dialysis n= 385 Age: mean 68	Cognitive impairment in 68%.(most pronounced in recall, attention and visual/executive function) Risk factors: older age, recent falls, cerebrovascular disease
Ha, 2013 (402)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Hamilton rating scale for depression (HAMD), Hamilton	Factors associated with depression	Single centre; patients on HD; n= 63 Age: >65: 34; 45-64: 39	Ex: Positive thinking and pain affected depression In older: positive thinking (p = 0.030) and pain score (p = 0.038) were associated with depression.

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			rating scale for anxiety (HAM-A), positive thinking scale (PTS), apathy evaluation scale, and degree of pain; life-style evaluated			
Hagren, 2001 (162)	Lived experience	Clinical Research	Qualitative analysis; analysis of interviews; interpretative design	Experiences of suffering from ESRD.	Single centre; Patients on HD; repeated interviews n= 15 Age: mean 62 (50 – 79)	the haemodialysis machine as a lifeline alleviation of suffering loss of freedom dependence on the caregiver disrupted marital, family and social life gaining a sense of existential optimism achieving a sense of personal autonomy
Hain, 2008 (403)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Linguistic inquiry and word count analysis; 3MS, GDS, Also Clinical, laboratory, socio-demographic variables, adherence at dialysis	Cognitive markers, relations to adherence and understanding	Single centre; older patients on haemodialysis n= 63 Age: 72.7 ±7.75	Cognitive impairment is common; poor adherence may be related to global cognitive impairment
Han, 2016 (404)	Lived experience	Clinical Research	Cross-Sectional Study, observational	to measure self-care behaviours in elderly hemodialysis (HD) patients and to identify	Single centre; patients on HD; n= 113 Age: elderly, n.s	Analysis of self-care behaviours reveals varying types. Age, education level, and social support predicted value accounted for 36.8% of the variance in self-care behaviours

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				variables associated with self-care behaviours.		highest scores: Caring for an arteriovenous fistula, followed by taking medication Lowest scores: engaging in social activities and diet control negative correlation : between self-care behaviours and serum phosphorus, and potassium, positive correlation: between self-care behaviours and social support
Harum, 2003 (405)	Lived experience	Clinical Research	Prospective Observational Study Tool used: 15 simple words (English and Spanish) in large print on 5 × 8 laminated 2-sided cards that were shown to the patient before, during, and after dialysis.	To determine the most effective time to administer nutrition education to hemodialysis patients by evaluating memory recall scores before, during, and after treatment.	Single centre; patients on HD (all Hispanic) n= 62 (> 65 - 32 patients, compared to <65- 29 patients) Age: Mean 62.4±13.2	Information best remembered when given just before HD Varying levels of cognitive function; best usually just before dialysis. Poorer recall - Older age, lower education
Ikaheimo, 2005 (178)	Lived experience	Clinical Research	Retrospective Observational study; Chart review	Describe the pattern of death on dialysis (comparing stop Vs discontinuation) in a single unit	Single centre; HD patients who discontinued dialysis n= 146 Age: mean 69	- Risk factors for withdrawal : older, institutionalised; dementia; less rehabilitated; treated for < 3 mths. - Good practice to get patients to think about withdrawal scenarios!

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Jassal, 2009 (406)	Lived experience	Clinical Research	Prospective Observational Study	Incidence of functional loss after starting dialysis	Single centre; All pts who started dialysis 2000-2005; functional loss defined as a permanent transfer to an assisted-living setting or nursing home or having submitted an application for caregiver support n= 97 Age: >80	In 6 months - 30% functional decline; stable after this. Most decline seems to occur in the first 6 months after initiation poor functional outcomes in relation to events occurring around the time of dialysis initiation?
Johansson, 2013 (407)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: nutritional assessments (3-day food diary, subjective global assessment, handgrip strength, and body mass index) and questionnaires: Short Form-12 (SF-12), the Hospital Anxiety and Depression Scale, the Mini Mental State Exam, and social networks.	Influence of psychosocial factors on the energy and protein intake of older people on dialysis	Single centre; patients on dialysis n= 106 Age: >65	Energy and protein intake in older people (regardless of modality) appears to be independently associated with psychosocial variables. Lower energy intake: - fewer social networks (P = .002) and lower PCS scores Lower protein intake:- Lower Index of deprivation score; an interaction between SF-12 PCS and presence of possible depression
Karolich, 2010 (408)	Lived experience	Clinical Research	Cross-Sectional Study; Interview- and Survey-based	Comprehension, manageability and	Single centre; ; Patients on HD	People differ in how they respond to the illness; individualised approach is necessary

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			Surveys used: Antonovsky's Orientation to Life Scale (OLS), interviews with those that scored the highest and lowest 5 scores; Health Management Survey (HMS) to measure adherence (survey created for the study)	meaning of illness in older people	n= 100 for quantitative data; of which 10 were chosen for qualitative analysis Age: 67.72 ± 10.25	High scores on OLS: adapted, internalised dialysis is part of daily life Low scores on OLS: view dialysis an illness as a central feature; overwhelmed, Dependent on others.
Kim, 2013 (409)	Lived experience	Opinion	Opinion paper	Frailty and protein-energy wasting		Frailty is common, multiple causes, associated often with PEW, leads to functional decline and poor QOL, mortality
Kittiskulnam, 2016 (63)	Lived experience	Review	Narrative review	Physical functioning and frailty; cognitive function; emotional health, including depression and anxiety; and health-related quality of life.		Physical Function: Elderly three times more likely to be frail Frailty - 2.5-fold risk of death & dialysis Cognitive function: CKD - higher cognitive dysfunction; dementia and Cognitive impairment - higher mortality Risk for development/worsening of pre-existing illnesses - like depression, anxiety; worsened by symptom burden

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Kurella 2009 (58)	Lived experience	Clinical Research	Cross-Sectional Study: USRDS data minimum data set	trajectory of functional status before and after the initiation of dialysis among elderly nursing home residents	Registry data; Nursing home residents who started dialysis n= 3702 Age: >60	Significant functional decline or death after starting dialysis for 87% of nursing home residents. Risk factors: older age, white race, cerebrovascular disease, dementia, hospitalization at the start of dialysis, & albumin < 3.5 Initiation of HD itself associated with this drop
Kutner, 2000 (173)	Lived experience	Clinical Research	Prospective Observational Study Surveys/tools used: Ordinal functional impairment index and life satisfaction rating, and Center for Epidemiologic Studies Depression Scale; Follow up: 3 years	To compare change over time in functional impairment, depression, and life satisfaction among older dialysis patients and age-matched controls.	Single centre; patients on HD n= 349 dialysis patients and 350 aged matched controls Age: >60	Older patients: - more functional impairment at baseline, and also at follow-up - higher depression scores at baseline, and also at follow-up - functional impairment and depression were significantly related. - dialysis patients reported lower life satisfaction at baseline than did controls, but the two cohorts were not significantly different on reported life satisfaction at follow-up,
Lacquaniti, 2009 (410)	Lived experience	Opinion	Opinion paper	Causes and types of malnutrition in dialysis patients		Malnutrition is common: moderate in 33%; severe in 8% Poor intake, dialysis complications and inflammation contribute
Li, 2004 (411)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based	Cognitive impairment in elderly continuous ambulator	Single centre; patients on CAPD compared	High prevalence of cognitive impairment in elderly CAPD patients compared to healthy elderly.

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			Surveys used: Cantonese MMSE; Clinical, laboratory, socio-demographic variables	y peritoneal dialysis (CAPD) patients	with healthy elderly n= 147 (81 elderly CAPD patients; 66 healthy elderly) Age: >65	Worse: females, increasing age. Protective: years of education. No effect: duration of dialysis, Kt/V, albumin and haemoglobin levels, and the number of comorbid conditions
Lim, 2010 (412)	Lived experience	Clinical Research	Retrospective Observational study Registry data; Clinical, laboratory, socio-demographic variables	Outcomes compared between younger and older PD patients.	Registry data; patients on PD n= 5176 Age: those over 65 compared to others	Elderly patients: higher peritonitis-related and all-cause mortality, superior technique survival and similar peritonitis-free survival, (suggesting that PD is a viable renal replacement therapy in this group of patients).
Llewellyn, 2014 (152)	Lived experience	Clinical Research	Qualitative analysis; of interviews	examine the narratives of older to illustrate how they managed to contain the intrusion of illness and maintain continuity in their lives.	Single centre; People receiving conservative management n= 19 Age: >73	Diagnosis of chronic illness in late life does not inevitably shatter lives or cause biographical disruption. Instead, people are able to construct continuity with complex narrative interpretations of diagnosis, sensation and treatment choices. 3 interactive phenomena mitigated the potential for disruption and allowed participants to maintain continuity: (a) the framing of illness as "old age"; (b) the prior experience of serious illness; and (c) the choice of the

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						treatment with the least potential for disruption.
Logan, 2006 (155)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Haemodialysis Stressor Scale and Jalowiec Coping Scale	Stressors and coping of older in-hospital haemodialysis patients	Single centre; Patients on HD n= 50 Age: >65	'Feeling tired' and 'limitations of fluid' were rated amongst the top five stressors The three coping strategies rated as being most used and helpful were 'keeping a sense of humour', 'look at the good side' and 'think positively'. Dialysis vintage had no effect Older participants: fewer strategies, found strategies less helpful.
Lovell, 2017 (179)	Lived experience; Information needs	Clinical Research	Qualitative analysis of interviews	Factors that influence decision-making about dialysis and dialysis modality in older adults; effects over time	Single centre; patients on HD; those About to start dialysis n= 17 Age: >65	Decisions as a fluid process, rather than occurring at a fixed point of time and was heavily influenced by perceptions of oneself as becoming old, social circumstances, life events and health status. Declining dialysis: independence and dependence The dialysis imperative: the need for length of life Delaying decision-making was common - waiting for a clinical directive; or for symptoms and physical decline

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						1. Maintaining one's independence - effect of dialysis 2. Need for support. 3. The choice as "dialysis or death". 4. The ability to delay a decision on dialysis 5. Significant impact of clinical directive from healthcare professional
Magnard, 2015 (167)	Lived experience	Clinical Research	he standing postural sway was measured using a Kistler force platform (model 9286BA) comprising two trials with stance with eyes open (EO) and stance with eyes closed (EC) measured in random order	effect of HD treatment on balance deficits in patients with ESRD	Single centre; patients on HD n= 12 Age: Mean 63; 51-83	The period after hemodialysis treatment is particularly unsafe, as evidenced by significant disability in postural control, Evident postural alterations were observed at post-hemodialysis balance assessment
Makaroff, 2013 (176)	Lived experience	Clinical Research	Qualitative analysis - analysis of interviews	The "un-sayable" aspects of experience in ESRD	Single centre; People living on dialysis were interviewed sequentially up to 4 times. Although interviewed for a different project, this was a reanalysis of the interview material. n= 14 Age: mean 66	Patients experience a variety of experiences that are difficult to talk about, including living with death, embodied experiences that were difficult to language. Speaking about death or dying is difficult for patients, even though they think about it

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Malavade, 2013 (413)	Lived experience	Opinion	Opinion paper	Review of dialysis in the elderly		- vascular access may be a burden to elderly - older patients often need assistance for home peritoneal dialysis - Functional decline, cognitive impairment common after dialysis initiation
Moustakas, 2012 (73)	Lived experience; Information needs	Review	Systematic review	Needs of older people with end-stage renal disease who have chosen simple scare	12 articles included	3 themes regarding needs were revealed: -Shared decision making -perception of quality of life -the role of educational resources Experience: 1. Decisions are often based on personal values beliefs and feelings towards life, not on effectiveness of treatment 2. Greater educational both patients and families required. 3. Patients' and nephrologists' opinions may differ. 4. Poor communication may be assisted by improved educational materials.
Murray, 2006 (414)	Lived experience	Clinical Research	Cross-Sectional Study; Surveys used: 9 validated neuropsychological tests. Cognitive performance was measured in three domains: memory,	Cognitive impairment in hemodialysis patients	Single centre; patients on HD; n= 338 Age: ≥ 55 years with an age-matched comparison group	Moderate to severe cognitive impairment is common and undiagnosed in hemodialysis patients. Severe impairment 37%, moderate 36%, normal 12%

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			executive function, and language.			
Namiki, 2010 (153)	Lived experience	Clinical Research	Qualitative research; analysis of interviews	challenges older people living with end-stage kidney disease and home haemodialysis face in their everyday life.	Single centre; patients on HD; n= 4 Age: >60	Findings indicated a transformed care dynamic, positive appraisal and active everyday engagement by participants. A positive outlook on life in the present - future purposeful and hopeful. Systems of partnership facilitated this 1. Accommodating haemodialysis at home (integrating into daily life for/reorganising) 2. Partnership - spousal: professional 3. The sense of self (ups and downs in the present; hope and uncertainty in the future)
Noble, 2009 (415)	Lived experience	Thesis	Qualitative analysis-interview-based study	Explore the experiences of patients and families with stage 5 CKD who had opted not to undergo dialysis	Single centre; conservative care population n= 49 - (30 patients and 19 carers) Age(patients on dialysis): mean 78 (Range: 68 - 91)	1. The decision not to have dialysis is not always straightforward: Can be of different types - either taken in an informed manner, considering the difficulties of dialysis; or the less informed decision. 2. Age considered a reason not to start dialysis. 3. Multiple symptoms; often requiring large

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						number of medications. 4. Uncertainties - approaching death, probable deterioration 5. Not talking about death
O'Connor, 2012 (17)	Lived experience	Review	Systematic review	To summarize evidence on conservative, nondialytic management of end-stage renal disease regarding 1) prognosis and 2) symptom burden and quality of life (QOL).	13 studies were included	Patients managed conservatively report a high symptom burden Preliminary studies suggest that QOL is similar. Findings are mixed as to whether dialysis prolongs survival; any survival benefit from dialysis decreases with comorbidities, especially ischemic heart disease.
Petersson, 2017 (163)	Lived experience	Clinical Research	Qualitative research; interviews	to explore adults' experiences of living with aPD.	Single centre; patients on PD; n= 10; Age: Mean 82.5	Older dialysis patients manage to achieve meaning in their lives Limitations and an uncertain future. 1) Facing new demands, 2) Managing daily life, 3) Partnership in care, and 4) Experiencing a meaningful life, leading to: comprehensive understanding: 'Striving for maintaining wellbeing'.

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Plantinga, 2017 (416)	Lived experience	Clinical Research	Retrospective Observational study Using Medicare claims data; Serious fall injuries were defined using diagnostic codes for falls in combination with fractures, brain injuries, or joint dislocation	Falls before or after dialysis therapy initiation	Registry data; Medicare beneficiaries among HD patients n= 81653 Age: >67	Falls risk higher after dialysis is started; incidence ratio 1.62. Risk higher in those more active: younger, had pre-dialysis care, albumin>3; able to walk and transfer, no assistance with ADL, not institutionalised
Racic, 2015 (165)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Comprehensive genetic assessment; Basic activities of daily living questionnaire, instrumental activities of daily living; The Timed Up and Go, Nutritional Health Checklist, Two Question Instrument for depression and Charlson comorbidity index	Compare dialysis and primary care patients, aged over 70, on components of comprehensive geriatric assessment	Single centre; Patients on dialysis. n= 106 dialysis patients and 300 primary care patients Age: >70	Older HD patients have poorer functional status compared to age-matched controls. Low IADL score, Impaired vision, Poor mobility and frequent falls - more common in elderly HD population
Rifkin, 2010 (158)	Lived experience	Clinical Research	Qualitative interviews; in phone or in person	Medication adherence behaviour and priorities among older	Single centre; predialysis patients n= 20 Age: Mean 72, 55 - 84	Polypharmacy leads to complex medication choices and adherence behaviours; discordant with conventional medical opinion;

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				adults with CKD		however, patients rarely discussed these with their physicians. Poor communication about side effects and medication decisions-worsens adherence.
Roberts, 2003 (417)	Lived experience	Clinical Research	Cross-Sectional Study; Patients asked about history of falls; screened for risk factors (postural hypotension)	To investigate whether postural hypotension and symptoms of hypotension and falls are common in older haemodialysis patients	Single centre; Patients on HD n= 47 Age: >70 23 patients underwent pre- and post-HD orthostatic BP measurement, 18 had ambulatory BP recording and 10 subjects had full autonomic function testing.	Elderly patients are at high risk of falls, hypotension, Dizziness, syncope/pre-syncope, autonomic dysfunction
Roberts, 2007 (418)	Lived experience	Clinical Research	Prospective Observational Study Falls questionnaire; to see if they reported falls, syncope, presyncope or dizziness.	to determine the incidence of falls and syncope and to look for any associations with routine clinical data.	Single centre; HD patients n= 78 Age: 32/78 were >65	Older haemodialysis patients have a high incidence of falls, syncope, presyncope or dizziness. only falls was age-related. 38% of patients aged >65 reported 1 or more fall compared to 4% of younger patients ($p < 0.001$). no significant differences in pre-dialysis, post-dialysis or standing BP between young and older or between fallers and nonfallers although the older patients did have a greater magnitude in

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						change between pre-dialysis BP and post-dialysis standing BP.
Rossier, 2012 (419)	Lived experience	Clinical Research	Prospective Observational Study Performance Oriented Mobility Assessment (POMA) test medical records, Mean follow up 20.6 months	Incidence, complications and risk factors for severe falls in patients on maintenance haemodialysis	Single centre; patients on HD n= 84 Age: Median 69.5 (29-85)	Severe falls in 28.6%; incidence 0.22 per patient-year; fractures in 54.8% of severe falls Falls are common; 4 risk factors - age, a past history of falls, malnutrition, depression POMA score of > 21 had a negative predictive value of 82%.
Russ, 2005 (156)	Lived experience	Clinical Research	Qualitative analysis of interviews	to consider the relationships between living and quality of life, dying and the awareness of (even the desire for) death, in dialysis - 'temporal subjectivity' for older patients	2 units in California; patients on HD; n= 43 Age: Most were >70	Choice; Incurability; Need to re-invent oneself. -difficulty in framing dialysis initiation as a choice -the amount of time required therapy -the lack of an end to treatment; the end of hope -being between life and death -contemplating death - life re-experienced
Seah, 2015 (168)	Lived experience	Clinical Research	Qualitative research - Semi-structured interviews	Exploring decisions to choose conservative care.	Single centre; ESRD, pre-dialysis patients referred to palliative care(advance care planning programmed) from the renal departments	Personal and contextual factors are important as people choose treatment options: Impact of ESRD - Physical and financial burden, coping techniques. Making the decision - immediate rejection of

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
					of 3 public hospitals in Singapore n= 9 Age: Median 81(61-84)	dialysis, personal ownership of decision, balancing the polls in reaching the final decision, age and life completion, financial and physical costs of dialysis, stories of suffering and burden inflicted by dialysis, inevitability of death. Feelings towards palliative management - satisfaction with decision, appreciation for medical teams
Sinclair 2012 (420)	Lived experience	Thesis	Qualitative analysis; interviews, pictures	Fluid restrictions in dialysis patients	Single centre; patients on HD: n= 7 Age: 39-82 years	Fluid restriction effects described as the following themes: magnitude of loss (loss experience from multiple social levels, individual levels, loss of freedom); the theme of constant struggle with fluid restriction (surveillance of intake, maintenance of low levels, downsizing or decreasing activities) and finally the theme of accepting (a life worth living, the support one receives, the consequences of not restricting fluid)
Sterky, 2005 (421)	Lived experience	Clinical Research	Prospective Observational Study; Tests used: "sit-to-stand" test (number of cycles within	To investigate the functional capacity of elderly HD patients	Single centre; patients on HD; Compared with age and gender	The HD patients in the study had a considerably lower functional capacity than the healthy subjects, this may have interfered with

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			10 s) and a staircase test (the number of cycles completed per second		matched controls n= 11 Age: >60	their daily living activities.
Stringer, 2012 (151)	Lived experience	Clinical Research	Qualitative analysis; 2 interviews, one at start and 6 months after dialysis	expectations of elderly patients starting dialysis and whether their views change after 6 months on this treatment.	Single centre; patients on HD; n= 22 Age: >65	expectations of patients change significantly throughout time on dialysis; several patients feel compelled by family to start dialysis 1. At start, 75% felt it would be easy to tolerate; and six months only 45% 2. 96% felt at the beginning the dialysis would make them feel better 3. 88% expected to live longer by having dialysis 4. Two themes regarding initiation: no choice; family compulsions (these patients were more likely to express regret at six months) 5. More receptive to advance care planning at six months
Sun, 2011 (149)	Lived experience	Clinical Research	Retrospective Analysis of discharge summaries from 1994 to 2009; extract data from medical records	Differences in hospital admissions between age groups	Single centre; Records of all patients on HD n= 382 Age: 166 were > 70	Number of hospitalisations similar between older and younger patients; number of hospital days are similar. Greater number of hospitalisations for infections as a percentage of total admissions among octogenarians

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Sunder, 2004 (422)	Lived experience	Clinical Research	Retrospective Descriptive study Comorbid illnesses, survival, hospitalizations and complications related or unrelated to peritoneal dialysis were reviewed	Descriptive study of elderly on peritoneal dialysis	Single centre; older patients on assisted PD n= 9 Age: >90	No increased rate of technique failure, hospitalisation, peritonitis or exit site infection. All episodes of infection successfully treated.
Tamura, 2009 (423)	Lived experience	Review	Narrative review	Incidence, management, and outcomes of end-stage renal disease in the elderly	Elderly and dialysis: mixed results – while mental components of QOL are stable, physical components decline. Survival much poorer than that of the young.	
Tan, 2018 (46)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Decision Regret Scale (DRS), information satisfaction, and decision-making involvement.	This study investigated (1) extent of patients' decision regret after starting dialysis, and (2) potentially modifiable predictors of regret, satisfaction with chronic kidney disease education,	Single centre; patients on HD; n= 103 Age: >70	Regret was more likely among those who experienced decisional conflict and/or expressed poorer information satisfaction. 81% of participants - no decision regret (DRS score <50), 11% ambivalence (DRS =50), and 8% regret (DRS >50). 19% felt dialysis had done them harm and 16% would not make the same decision again.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
				decisional conflict, and decision-making involvement		
Thomas, 2016 (424)	Lived experience; Information needs	Clinical Research	Qualitative analysis; Semi structured interviews; Patient and carer group developed and conducted the interviews	experiences of older people (> 70 years) in the shared decision-making process through interviews conducted by patients, carers and health care professionals	Single centre; Patients who had made a decision to start or not start dialysis within the previous six months n= 29 Age: mean 77.4	The majority of patients were involved in the dialysis decision. Other aspects of experience: 1. Delaying the decision to start dialysis 2. The decision-making continuum - sharing; role of hcp; role of family; too much information; information gained from other patients 3. The reality of dialysis - not enough knowledge about the negative aspects Information needs: quality of the information provided could be improved, especially: - how daily living can be affected by dialysis. - difficulty with knowing what questions to ask because of lack of adequate information about the treatment -information was too complex, difficult to understand

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						- Having family members was important -information also gathered from informal sources/casual discussions (other patients, etc.)
Tyrrell, 2005 (425)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: depression scale (MADRS), two cognitive tests (MMSE and BEC 96), and a quality of life questionnaire (NHP).	Levels of cognitive impairment, depressive mood and self-reported quality of life in older dialysis patients (>70 years).	Single centre; HD patients n= 51 Age: >70	Cognitive impairment and depressive mood are often overlooked and underestimated in this population. Depression 60%; Cognitive impairment up to 47% 50% of those depressed also had cognitive impairment
Ulutas, 2016 [217]	Lived experience	Clinical Research	Cross-sectional Study; Surveys used: MMSE, TUG, chair stands; ADL, IADL scales	To assess functional dependence of patients opting for PD	Single centre; Patients on PD n= 74 Age: 76.2 ± 7.5	Impaired physical and functional performance is common in older PD patients
Van Loon, 2017 (57)	Lived experience	Clinical Research	Prospective Observational Study Survey used: KDQOL-SF; followed up for two years	Influence of age and time on the physical function of patients on dialysis	Study data; CONTRAST study; patients on HD n= 386 Age: Over 65 compared to less than 65	Ex: very few hemodialysis patients maintain a good physical condition over a 2-year time span. Especially in older patients, physical performance is poor, and decline is faster than in the healthy population. 15% (one in six) succeeded in maintaining a good physical condition overall; over 75, this was 3.6%.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						Declining physical function: increasing age (OR 1.96 to 2.38); and albumin (1.14 per gram decrease)
Walker, 2012 (157)	Lived experience	Clinical Research	Qualitative analysis; analysis of interviews	experiences of older patients attempting to integrate lifestyle changes into their lives	Single centre; patients on HD; n= 9 Age: >60	Impaired Ability to change lifestyle or adherence due to: 1. Self in relation to others (burden to others, receiving help, relationships with hcp). 2. Control (self-monitoring; disclosure or concealment of the illness; decision-making) 3. Adherence (dietary decisions are a burden; establishing a routine helps) 4. Beliefs about illness and treatment (thoughts of side effects; medication to harm; value) 5. Uncertainty
Yaffe 2010 (426)	Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Modified Mini-Mental Status Examination (3MS), Trails A and B, Category (verbal) Fluency, Buschke Selective Reminding Test	Cognitive impairment in older; see if relationship between CKD and cognitive function is independent of demographic and clinical factors	Study data; CRIC study; participants with eGFR <30 n= 157 out of 825 Age: >50	13-18% of cognitive impairment with CKD 1.5 to 2.6 unadjusted odds ratio of clinically significant cognitive impairment when GFR less than 30; not dependent on race/gender/ age diff here

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			(immediate and delayed memory), and Boston Naming.			
Ameling, 2012 (38)	Information needs	Clinical Research	Mixed Methods studies for development of education aids - including interviews, focus groups.	Design, and evaluation of a decision aid for patients with ESRD and varying levels of health literacy, health numeracy, and cognitive function	Several groups of identified patients , interviewed through multiple iterations	1. Patients wanted information in simple terms, simplifying complex medical terminology; manageable bites; and real-life examples to explain concepts. 2. After multiple iterations the decision aids addressed: mortality and morbidity; general health problems; autonomy; treatment delivery; symptoms; relationships; psychological effects (feelings) and finance or money matters
Burns, 2010 (8)	Information needs	Opinion	Opinion paper	Conservative management for CKD		Symptoms, length of life, quality of life, frequency of visits, support available, Mode and place of death
Chanouzas , 2012 (427)	Information needs; Lived experience	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: Postal questionnaires; participants are asked to rate factors according to influence on the choice of modality	How personal and demographic parameters affect dialysis treatment choice	Single centre; Patients registered at a pre-dialysis centre n= 118 Age: All ages; mean: 55 for PD; 68 for HD; 84 for CM	Ability to cope, verbal/written information about modality, fitting modality with lifestyle & distance / travel to the centre - Patients that were older and had more comorbidities tended to choose conservative management.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						Several personal factors dictate choice of treatment modality - being married, being employed, having another person living at home. Including: ability to cope, fitting modality with lifestyle, distance to centre and verbal/written information about modality. Age affected choice (PD 55, HD 68, CM 84). Degrees of comorbidity (4.1, 5.8, 7.7).
Elliott, 2013 (161)	Information needs	Opinion	Opinion paper	Age and treatment of kidney failure		Information needs: Full exploration of patient's wishes; supporting the decisions; provision of adequate information (including disadvantages/outcomes with dialysis in the elderly)
Fine, 2005 (428)	Information needs	Clinical Research	Qualitative analysis; Questionnaire-based survey	First time patients; how much information they would wish their physician to provide about dialysis treatment, including survival.	Single centre; Patients at their first visit in nephrology clinic; older patients, but no description of their renal function status. n= 100 Age: 64 ± 14	97% wanted to know about life expectancy of dialysis limitations and quality of life, side effects, and how effective treatment has been on patients of similar age and comorbidity. 95% of patients requesting life expectancy information did so because they could be better prepared. A majority consider that knowing about

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						outcome might alter both future lifestyle and decisions regarding dialysis. Majority want physicians to disclose life expectancy data without prompting and to be given as much information as possible, both good and bad.
Fine, 2007 (102)	Information needs	Clinical Research	Qualitative analysis; Questionnaire-based survey	To explore whether patients would want their physician to disclose, without prompting, prognostic information should they require dialysis in the future, whether the prognosis be good or bad	Single centre; Patients with CKD 3 and 4 attending a multidisciplinary clinic; 28% had renal education classes, 46% had not graduated from high school; 37% knew someone on dialysis. n= 100 Age: 66±16	92% wanted to know life expectancy on dialysis. 98% wanted to know limitations on quality of life on dialysis. 89% wanted disclosure of as much information as possible, whether good or bad. The most common reason 89% for wanting disclosure of life expectancy was to be better prepared to accept what happens on dialysis. 82% wanted physician to disclose life expectancy without having to be prompted.
Harwood, 2013 (40)	Information needs	Review	Systematic Review	Decision-making; influence of context	16 studies included	Choice: Alternative forms of treatment Discussion regarding intrusiveness and how to minimise this (daily routine, distance, travel, et cetera) Role of knowledge and information from other sources, including peers on dialysis

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						the knowledge that decisions are highly influenced by the personal characteristics, family values, context of patients' lives, desire for minimal intrusiveness. Information: relevant, timely, considering needs of family as well as impact on lifestyle
Harwood, 2014 (41)	Information needs	Clinical Research	Qualitative analysis; Ethnography; critical realism to explain complex decision-making	Personal and structural facilitators and barriers for home-dialysis decision-making	Single centre; Patients from a multidisciplinary CKD clinic as well as the healthcare professionals. n= 13 patients, 4 HCPs Age: >65(mean 74.3)	About dialysis; its effects on lifestyle; the need for support; the difference in information seeking behaviours Themes : precariousness with limited choices; personal factors (age, knowledge about dialysis; lifestyle and effects of dialysis; learning their options); gender differences in approach to learning (men did not seek the information; tends to delay decisions); the necessity of support
Hussain, 2015 (42)	Information needs	Review	Systematic review and thematic synthesis	qualitative studies of factors affecting patients' or health care professionals' decisions to commence or withdraw	12 studies, 206 patients, mostly HD, 64 HCPs	Physician style and patient style (delivery and receipt of info) have impacts; -patient factors, health care professional factors, and their interaction determined decisions. - Whether the effect on QoL outweighed survival advantage, or vice versa, was a

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
				from dialysis.		personal judgment, and not something health care professionals and family members could predict - Interaction: Power and communication ; effects of patient and physician styles - Communication of uncertainty led to fear; avoidance of decision-making - Patients preferred more rather than less information about the future
Johnston, 2012 (429)	Information needs	Clinical Research	Qualitative analysis: Analysis of patient-provider Interactions, transcribed verbatim	Exploration of patients' decision-making	Single centre; patients at a CKD clinic discussing Conservative management with their doctors. n= 9 Age: mean 86	Patients opting for conservative management gave numerous reasons, including old age, travel limitations, feeling well without dialysis and not wanting to be a burden. Stability of overall health. Contentment with decision
Ladin, 2015 (430)	Information needs	Opinion	Opinion paper	Patient-centred information		1. Promote shared decision-making 2. Support caregivers in decision-making and provision of care 3. Provide culturally sensitive, tailored approaches to renal palliative care 4. Promote end-of-life planning

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Ladin, 2018 (431)	Information needs	Clinical Research	Qualitative analysis; semi structured interviews; Clinical, laboratory, socio-demographic variables	Exploration of health literacy (functional, interactive and critical) in patients at End-of-life discussions	Single centre; dialysis patients n= 31 Age: >65	lack of understanding of medical terminology (prognosis, hospice, quality of life, interventions); physicians reluctant to discuss prognosis and end-of-life issues; discordant expectations and dialysis experiences (problems with health literacy, especially the functional and interactive aspects)
Loiselle, 2016 (180)	Information needs	Clinical Research	Qualitative analysis: Interviews with several groups of stakeholders - patients and HCPs	Decision-making needs from the perspectives of patients, professionals, and others involved in the decision.	Single centre; Many groups of participants, 3 Patients, 5 doctors, 5 nurses, 1 supervisor, 1 other professional Patient group n= 3 Age: with 70 - 79	Initial support needed with emotional issues; Lack of pressure from others in the initial phases; adequate follow-up; appropriate provision of information (not overload; always accessible); different information according to stages; validation and reassurance from clinical professionals
Mandel, 2017 (43)	Information needs	Opinion	Opinion paper	Serious illness conversations in ESRD		1. 90% of dialysis patients believe it is important to know prognosis or how the disease will progress 2. Information about procedure and admission rates 3. Absence of knowledge leads to overly optimistic expectations of longevity and outcome. 4. Patients expect serious illness conversations to occur

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						early in the disease course. 5. Conversations during the time patients are on dialysis can be difficult because of cognitive issues; privacy issues; time and space constraints. 6. Preference on patient centred goals and preferences (symptoms, quality of life, suffering) rather than dialysis procedures/disease management, as preferred by doctors. 7. Need for adequate relaying of information between sources. (Dialysis units often not aware of discussion between patient and doctor)
Manian, 2015 (432)	Information needs	Opinion	Opinion paper	End-stage Kidney disease at the end of life		Patients Considering stopping dialysis should receive more information about the symptoms and modes of death
Morton, 2010 (433)	Information needs	Review	Systematic Review	Views of patients and carers in decision-making, factors influencing those decisions.	18 studies included	Central themes: mortality; lack of choices; information about options; peer information is valued; how options are weighed

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Noble, 2006 (434)	Information needs	Audit	Audit	End of life care	Single centre; Patients dying on a renal ward	Family need to be informed, involved - dying patients often too unwell to be involved; underscores importance of Advance care planning
Okamoto, 2015 (105)	Information needs	Clinical Research	Qualitative analysis; Interviews with Renal health-care professionals (HCPs)	Shared decision-making	Study data; Multicentre; HCPs across several Renal units, study, CKMAPPS (Conservative Kidney Management Assessment of Practice Patterns Study), U.K. n= 60	1. Decision-making often happens in a confusing/uncertain context. 2. The advantages of shared decision-making. 3. Situation of uncertainty - regarding prognosis, future treatment rather than a current one; Patients that change their mind. 4. Coping with uncertainty: shifting choice to patients or to guidelines; difficulties patients have with making choices; The benefits of making a firm decision that does not change. 5. "Good" outcomes; and death; good not only from the patient's point of view, but also from the doctor's point of view.
Parvez, 2015 (99)	Information needs	Opinion	Opinion Paper	How uncertainty is conveyed		Information needs: Patients are anxious with uncertainty, but it can be an opportunity for shared decision making; providers need to incorporate uncertainty into the

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
						discussions; this can foster trust
Russ, 2012 (37)	Information needs	Opinion	Opinion paper	Decision-making in older adults		Patients tend to go along with current therapy rather than actively make choices; provision of information tailored to the patient's situation is relevant; prognostic information and information about life on dialysis/course after discontinuation will be useful.
Schell, 2011 (182)	Information needs	Clinical Research	Qualitative analysis; Focus groups and interviews	To document how prognosis is communicated by nephrologists and understood by patients	Single centre; Patients on dialysis and their nephrologists n= 28 patients over 65 on dialysis or with advanced CKD; and 11 nephrologists. Age: >65	Nephrologists: discussions of prognosis were infrequent; generally prompted by the patient or a decline in clinical status; barriers: insufficient time, potential negative impact on patient hope, lack of privacy. Patients: information received using medical terminology: discussions regarding blood chemistry; less emphasis on prognosis; fear and worry about impending dialysis; little thought about the future (uncertainty; lack of knowledge about the future)

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Schell, 2012 (20)	Information needs	Clinical Research	Qualitative analysis; focus groups and interviews	To describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy.	Single centre; Patients with advanced CKD in dialysis education clinics; on dialysis; their nephrologists n= 29 patients and 11 nephrologists Age: >65	Patients need information about: diagnosis, progression, prognosis, effects on daily life Nephrologists: - struggled to explain disease complexity - manage a disease over which they have little control - tend to avoid discussions of the future - prognosis discussions are rare
Schell, 2014 (44)	Information needs	Opinion	Opinion paper	Communication framework for dialysis decision-making; aligning treatment choices with patient goals and values.		This communication framework suggests providing information regarding: Prognosis and end-of-life; benefits vs risks of dialysis; preparation for future setbacks; possibility of a time-limited trial; features suggesting poor outcome; potential burdens of dialysis and their effects; explore understanding of and expectations from dialysis; provide a recommendation; provide empathy; discuss patient's specific values; patient's worries and concerns; outlining milestones and pause points; documenting and revisiting the plan

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Selman, 2018 (435)	Information needs	Clinical Research	Qualitative analysis; In-depth qualitative interviews with a purposive sample of older patients with chronic kidney disease stage 5 in 3 UK renal units; Conference abstract	To explore views and experiences of communication, information provision and treatment decision-making among older patients receiving CKM	Single centre; older patients receiving CKM n= 20 Age: mean 82	1. Staff-patient communication and provision of information - clinicians can be rushed, avoid discussion 2. Nursing conversations and gaps in information provision 3. Information preferences - wanted: treatment options and disease; ambivalent: knowing details of text in the stage 4. Treatment decision strongly influenced by the clinician's views, recommendations and reassurances
Song, 2013 (436)	Information needs	Clinical Research	Qualitative analysis; Semi structured interviews; informed decision-making questionnaire (developed by investigator)	Patients' views of dialysis decision-making experience	Single centre; Patients on dialysis; elderly (>65 years) patients' views about their decision-making experience after starting dialysis in comparison with patients aged 50–64 years, and patients <49 years. n= 32 (over 65; out of a total of 99) Age: >65	1. What to expect with dialysis 2. Informed decision-making scores were significantly lower for the older. 3. Older-doctor did not explain conditions that lead to kidney failure or impact on daily life or the lifelong need for dialysis 4. Older - doctor did not check if I understood

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
Thorsteinsdottir, 2012 (437)	Information needs	Opinion	Opinion paper	Treatment options in the elderly patient		Patients want to know about prognosis - refers other included studies, which were inclusive of patients of all ages
Tonkin-Crine, 2015 (68)	Information needs	Clinical Research	Qualitative analysis; Interviews with patients	Reasons for selecting dialysis or conservative management	Single centre; of 42 purposively sampled pts from 3 groups: 14 patients with stage 5 CKD who planned to initiate dialysis, 14 patients who had recently initiated dialysis, and 14 patients who had elected conservative management n= 42 Age: >75	Patients require information of all options, including conservative care, Advantages/disadvantages of dialysis vs conservative care, Understanding of symptoms and illness trajectories (to prevent changing of decisions); Discussions about transport options; Understanding of discussions with healthcare professionals particularly with regards to prognosis.
Zimbudzi, 2017 (438)	Information needs	Clinical Research	Cross-Sectional Study; Survey-based Surveys used: The Diabetes Renal Project Patient Survey, Diabetes Renal Project Doctors Survey, the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire, the Kidney Disease Quality of Life short form	Factors associated with patient 'activation' (greater role in managing on health care)	Multicentre; patients attending diabetes and renal outpatient clinics of four public tertiary hospitals n= 305 Age: median 68	Older patients score lower on activation scores; Greater burden of kidney disease and lower MCS on QOL scores predict poor activation. These factors may need to be addressed prior to patient engagement.

Author - Year	Outcome - Area of Interest	Type of Paper	Methods	Parameters studied	Population	Main Findings - Comment
			(KDQoL-36) and the Patient Activation Measure (PAM-13)			

Appendix 2: Supplementary material for Chapter 4

Participant interview guide

1. Introduction
    a. Introduce yourself.
    b. Explain purpose of study; how interview is to be conducted and analysed.
    c. Offer option to review and edit interview after recording or transcription.
2. Participants' perception of outcome
    a. How are you doing on dialysis? (Are you doing well or poorly?)
    b. Why do you think you are doing that way? (Explore what the participant's thoughts on what affecting the outcomes on dialysis).
3. The experience of being on dialysis
    a. What are the best and worst things about life, in general, for you now?
    b. What are the best and worst things for you about life on dialysis?
    c. If you were not on dialysis, what would you be doing?
4. Relationships
    a. How do the people around you influence how you cope with dialysis? (Role of family, friends, social networks)
    b. Tell me about your relationships with nurses / doctors. (How do you get along? Can you discuss all your concerns with them? What role do they play / how do they help?)

6. Managing life on dialysis
    a. Regarding practical things (activities of daily living, money, transport, food) – how much do you still do?
    b. How much do others help? Who helps?
7. Thoughts of the future
    a. How do you see the future playing out?
    b. Have you thought about treatment options if you were to be seriously unwell? (explore thoughts regarding advance care planning, healthcare proxies)

Table A-17: Consolidated criteria for reporting qualitative studies (COREQ)

No.	Item	Comments
Domain 1: Research team and reflexivity*		
1	Interviewer/facilitator	**BB**
2	Credentials	**BB** -Masters in Public Health; BN; Cert. in Neph. Nursing; **RR** - DM, MRCP(UK), FRACP, PhD candidate; **MF** – PhD (Psychology); **KA** – MSc Clinical Trials, PhD; **MJ** – FRACP, FASN, PhD
3	Occupation	**BB**-Nurse; **RR,MJ**- Nephrologist; **MF**-Qualitative researcher; **KA**- Research Scientist & Educator,UTAS
4	Gender	**BB**- Female
5	Experience and training	**BB** (interviewer) – Formally trained in qualitative research, interviewing; **RR** (primary author and analysis) – Trained in qualitative research
6	Relationship established	Some participants known to **BB, RR**
7	Participant knowledge of the interviewer	**BB** is a nurse with experience in dialysis **RR** is a Nephrologist undertaking research towards his PhD
8	Interviewer characteristics	**BB** is a nephrology nurse with interest in pre-dialysis education and supportive care; **RR** is a nephrologist with

		interest in outcomes in the elderly with renal failure; and is a PhD candidate at the University of Tasmania
Domain 2: study design		
9	Methodological orientation and Theory	Phenomenology; iterative thematic analysis
10	Sampling	Convenience sampling
11	Method of approach	Face-to-face
12	Sample size	n=17
13	Non-participation(reason)	n=1; "not interested"
14	Setting of data collection	Participant's homes (n=14) or dialysis unit (n=3)
15	Presence of non-participants	No
16	Description of sample	Participants aged ≥70 years (range 70–83); undergoing dialysis in the period 2014-2016; all Caucasian, English-speaking; 11 males, 6 females; none were employed
17	Interview guide	Attached. Yes, pilot tested.
18	Repeat interviews	No.
19	Audio/visual recording	Yes. Audio recordings.
20	Field notes	Yes.
21	Duration	45 minutes (range 30 to 75 minutes)

22	Data saturation	Yes
23	Transcripts returned	Participant offered chance to review; none requested this.
Domain 3: analysis and findings		
24	Number of data coders	RR/BB/MF
25	Description of coding tree	No
26	Derivation of themes	Derived from data
27	Software	NVivo qualitative data analysis Software; QSR International Pty Ltd., Australia. Version 10, 2014
28	Participant checking	No. Participants offered chance to check; none requested this.
29	Quotations presented	Yes; identified by anonymised participant numbers
30	Data and findings consistent	Quotations provided to illustrate each theme
31	Clarity of major themes	Yes; identified as metathemes (Table 2)
32	Clarity of minor themes	Yes; see text under 'Results' and Table 2

*__BB__ – Mrs Bridget Brown; __RR__ – Dr Rajesh Raj; __MF__ – Dr Mai Frandsen; __KA__ – Dr Kiran Ahuja; __MJ__ – Prof. Matthew Jose

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